PROVIDING INFORMAL CARE:

HOW TO FACILITATE RESILIENCE IN CHALLENGING TIMES

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy

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CONTENTS

List of tables and figures

Tables

Figures

Abstract

This thesis uses qualitative and quantitative methods to identify and explore resilience in informal carers using Windle and Bennett's (2011) ecological framework. First, we[1] explore the ecological framework in older informal carers. We reveal that older spousal dementia carers and non-spousal informal carers can achieve resilience. Carers draw on assets and resources from across the resilience framework which interact with each other to facilitate resilience. Next we investigate the mechanisms through which emergent themes facilitate resilience over time. We find that older people display a positivity bias, with some evidence to suggest that this is more pronounced in older carers than older non-carers. We reveal that resilient and non-resilient carers share structurally and functionally similar support characteristics. Non-resilient carers are more likely to resist over-involved family support and resilient carers are more likely to receive support from friends with shared experience. Finally, we find that carers can remain or become resilient over time. Institutionalisation and widowhood provide opportunities to draw on more assets and resources. Together, the findings suggest that informal caregiving is not entirely burdensome; carers can achieve resilience and draw on several assets and resources from across the resilience framework. The findings emphasise the importance of social ecological approaches to resilience. However, resources are not always sufficient to facilitate resilience; practitioners and policy makers should deliver personalised carer services that match need.

[1] First person plural used throughout to maintain continuity with published chapters.

Declaration

No portion of this work has been submitted in support of any other application for degree or qualification at this or any other University or Institute of learning.

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First, I'd like to thank the carers who talked to me about their experiences. I'd like to thank Joanne Hornby and Joanne Crompton who gave me time and space out of their busy schedules to conduct my research.

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Finally, thanks go to my family. To those I have lost; my Dad and my little boys Joseph and Niall, you live on in everything that I am and everything that I do. I'd like to thank my son James, whose chapters start as mine end; Bernadette for putting up with me; Craig for being quietly proud of me; Auntie Marie for being my biggest supporter. Mum, the personification of resilience; I could dedicate a thousand theses to you and it wouldn't come near to what you've done for me.

Dissemination

In line with the University's guidelines for submission of thesis by published papers, this thesis conforms to an 'article format' in which Chapters 3 and 6 are submitted as published papers, Chapters 4 and 7 are under review, and Chapter 5 is being prepared for re-submission. Each Chapter is self-contained and, as a result, some literature and figures are replicated. Furthermore, we use first person plural throughout to maintain continuity with published Chapters. Brief forewords are provided at the beginning of each Chapter explaining how they link to preceding Chapters.

We originally intended for Chapter 4 to come before Chapter 3 as it focuses on a more general non-spousal carer sample. However, Chapter 3 was accepted for publication and there was a delay in acquiring the CFAS Wales data set. We placed Chapter 3 first to avoid Chapter 4 self-citing work that had not yet appeared in the thesis.

Contributor statement

Warren Donnellan was primarily responsible for the conception and design of the studies in this thesis. Drs Bennett and Soulsby provided additional direction in conception and design.

Warren Donnellan was solely responsible for data collection, data analysis, data interpretation and drafting of initial manuscripts. Warren Donnellan is first author on all published articles and peer-reviewed manuscripts.

Warren Donnellan was primarily responsible for critical revisions of submitted manuscripts. Drs Bennett and Soulsby provided additional feedback.

Empirical work in peer-reviewed publication form

Chapter 3 was accepted for publication in Aging & Mental Health on 13/10/2014 (Manuscript ID: CAMH-2014-0216.R1):

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health*, 19, 932-939.

Chapter 6 was accepted for publication in Aging & Mental Health on 01/07/2016 (Manuscript ID: CAMH-2016-0087.R1):

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2016). Family close but friends closer: Exploring social support and resilience in older spousal dementia carers. *Aging & Mental Health,* DOI: 10.1080/13607863.2016.1209734.

We refer to our published work throughout the thesis using the journal references rather than Chapter numbers. Footnotes are used to denote important additional references that were not cited in the published article.

Empirical work under review

Chapter 4 was submitted as a manuscript to Gerontology on 25/02/2016 (Manuscript ID: 201602005). Rejected on 30/03/2016. Reviewer's comments have been addressed in the Chapter. Chapter 4 was submitted as a manuscript

to Research on Aging on 13/1/2017 (Manuscript ID: ROA-17-012). Awaiting reviewer feedback.

Chapter 7 was submitted as a manuscript to Aging & Mental Health on 22/11/2016 (Manuscript ID: CAMH-2016-0504). Awaiting reviewer feedback.

Empirical work in preparation for re-submission

Chapter 5 was submitted as a manuscript to the Journals of Gerontology Series B: Psychological Sciences and Social Sciences on 11/12/2015 (Manuscript ID: JGPS-2015-323). Rejected on 21/01/2016. Reviewer's comments have been addressed in the Chapter. We are preparing for re-submission to the same journal with additional data.

PART ONE

INTRODUCTION TO THE THESIS

Chapter 1

Overview of the thesis

1.1 Introduction

This thesis aims to use Windle and Bennett's (2011) resilience framework to identify and explore resilience in informal carers. We use Windle's (2011) definition of resilience: "The process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity" (p. 163). This thesis extends the existing literature in terms of theoretical development, research methodology and sample. First, we conduct an extensive literature review before introducing the aims of the research. Second, we use qualitative and quantitative methods to explore the ecological resilience framework in older informal carers. Third, we use quantitative and qualitative methods to investigate some of the mechanisms through which assets and resources facilitate resilience over time. Finally, we synthesise research findings and consider the outstanding issues and future directions of the research. See Figure 1.1 for diagrammatic representation of thesis structure.

1.2 Structure of the thesis

1.2.1 Part one: Introduction to the thesis

The thesis begins by presenting the main background literature and theoretical framework before introducing the aim and research questions (Chapter 2).

1.2.2 Part two: Exploring the resilience framework in older informal carers

The second part of the thesis presents two Chapters that explore the ecological resilience framework in older informal carers. Using qualitative methods, Chapter 3 classifies older spousal dementia carers as resilient or not, identifies the factors associated with resilience, and examines whether they can be mapped on to the resilience framework. Using quantitative methods, Chapter 4 draws on CFAS Wales data to consider the predictive relationships between individual assets, community and societal resources and resilience in a non-spousal carer sample.

1.2.3 Part three: Investigating emergent mechanisms of resilience in informal carers

The third part of the thesis takes key themes to emerge from part two and explores the mechanisms through which they facilitate resilience in informal carers. Part two highlights the need for longitudinal resilience research and identifies staying positive and social support as key components of resilience. Using quantitative methods, Chapter 5 explores the age-related positivity effect in carers and non-carers across the life course. Chapters 6 and 7 extend and further explore data utilised in Chapter 3. Chapter 6 explores the availability, function and perceived functional aspects of support and resilience in older spousal dementia carers. Using qualitative longitudinal follow-up data, Chapter 7 examines changes in resilience, assets and resources through care status transitions in older spousal dementia carers over time.

1.2.4 Part four: Discussion and conclusions

The thesis concludes with a synthesis of the main findings in view of the research questions. Chapter 8 provides an overview and theoretical implications of the findings, makes recommendations, considers the outstanding issues and future directions of the research and draws conclusions.

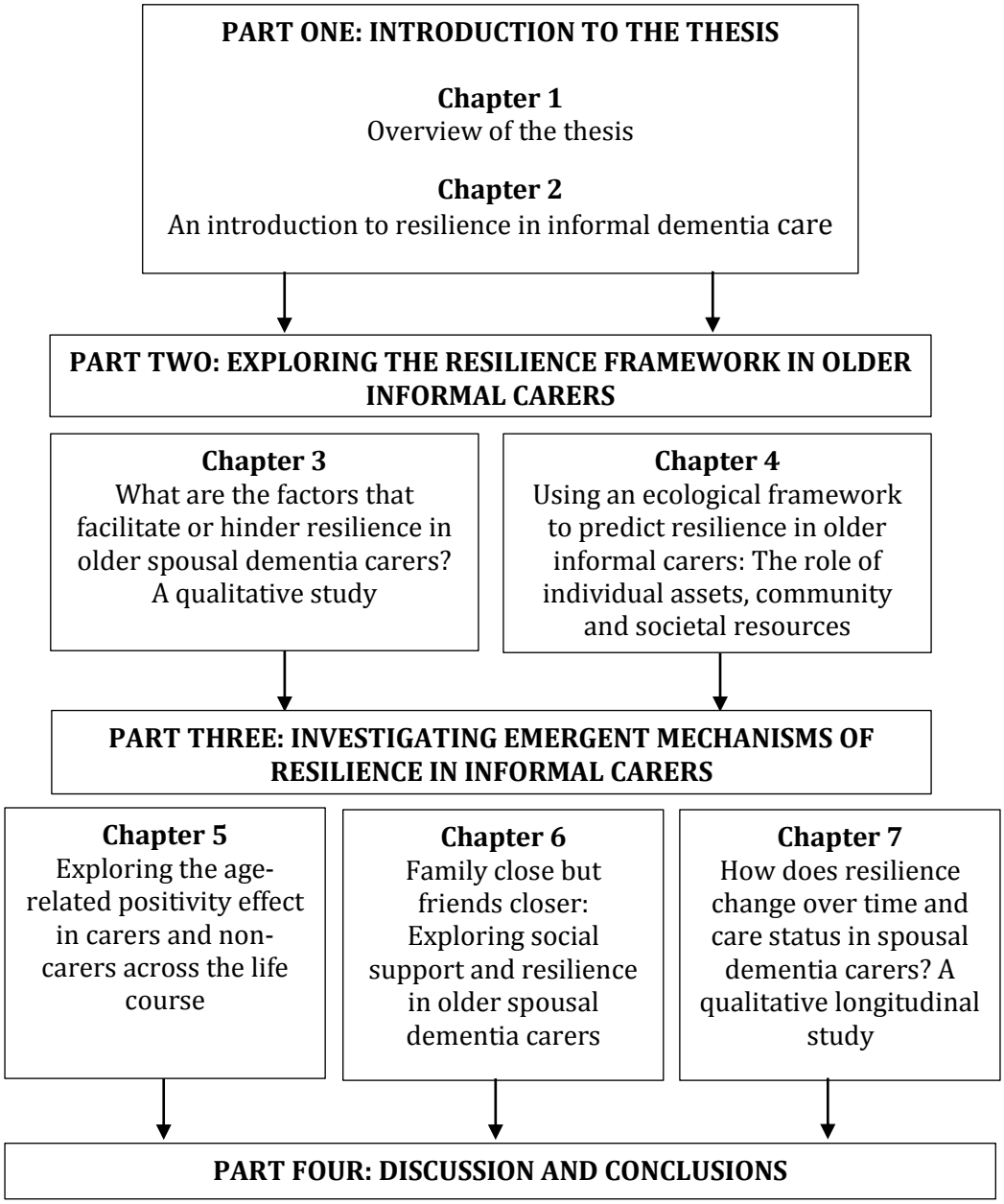

Figure 1.1: Diagrammatic representation of thesis structure.

Chapter 2

An introduction to resilience in informal care

2.1 Foreword

This Chapter introduces the relevant literature and provides an overview of the main theoretical and methodological framework used throughout the thesis. It provides a summary of the informal caregiving context, including dementia care, and considers important aspects of the literature, including caregiver burden. It then moves to definitions, mechanisms and ecological aspects of resilience, summarising the research on individual, community and societal resources that facilitate or hinder carer resilience. It ends by outlining the methodological approach used and how rigour was ensured. Further relevant literature will be discussed in each Chapter.

2.2 Carer demographics

An informal carer is defined as "an individual who provides unpaid, needed care on a long-term basis to a care recipient, who is most often a relative, friend, or neighbour" (Outreach Survey, 2002; p. 89). Since 2001 there has been an 11% rise in the number of informal carers living in the UK, rising from 5.8 million to 6.5 million (Office for National Statistics, ONS, 2011[a]). This figure is likely to reach 9 million by 2037, as the proportion of dependent to independent people is increasing, and people are living longer with complex health and social care needs (Bond & Cabrero, 2007; Carers UK, 2015). According to the ONS (2011[a]), around two million of these unpaid carers are aged 50-64, and 1.3 million are aged 65 or older. Older carers are the fastest growing carer cohort in the UK,

and those aged 85 and over are most likely to be providing more than 50 hours of care per week (Morbey, 2015).

In addition, approximately 75% of informal carers are caring for older people (Pickard, 2004). According to the National Health Service (NHS; 2010), most carers provide care to their parents or parents-in-law (58%), whilst 26% care for their spouse or partner. Half of carers are currently living with the person they care for, and half care for someone in a different household (NHS, 2010). The majority of these 'distance carers' live within a 30-minute journey of the care recipient (Carers UK, 2015). There are more women than men providing care (ONS, 2011[a]). However, there are age differences in these demographics. For example, middle-aged carers are most likely to be female (58%) and caring for their parents or parents-in-law in a different household (NHS, 2010; ONS, 2011[a]). Many of these carers are likely to be 'sandwich carers': caring for multiple people across multiple generations (Grundy & Henretta, 2006). Older carers are most likely to be male (59%) and caring for their spouse or partner in the same household (NHS, 2010, ONS, 2011[a]).

The type of care that carers provide varies considerably. According to the NHS (2010), approximately 82% of carers provide practical support, such as preparing meals and doing the laundry. 38% provide personal care and physical help to care recipients. Many carers provide less traditional support, including keeping an eye on the care recipient and keeping them company. Type of care varies by care frequency and living arrangements. For example, carers who provide 20 or more hours a week of care and those who live with the care recipient are more likely to provide personal care, physical help and administer medications (NHS, 2010). 'Sandwich carers' are more likely to be providing

lower levels of care, as they combine caring with work and childrearing commitments (Grundy & Henretta, 2006).

2.2.1 Carer demographics and caregiving experience

Complex demographic characteristics influence the caregiving experience. The relative contribution of demographic factors is mixed across studies. For example, there are inconsistent findings for gender differences in depressive symptomology, life satisfaction, or loneliness, although it is clear that women of all ages are more burdened by caregiving than men (Etters, Goodall, & Harrison, 2008; Gibbons et al., 2014; Jessup, Bakas, McLennon, & Weaver, 2014; Pöysti et al., 2012; Takano & Arai, 2005). Calasanti and King (2007) argue that caregiving is more difficult for women due to role expectation and less delegation of care duties. Russell (2007) argues that, rather than experiencing less burden, men may express and handle their burden differently than women, taking a managerial and stoic approach to caregiving (Cherry et al., 2013; Gilbert, Ussher, & Perz, 2014).

Zhou, Yi, Zhang and Wang (2014) found that carers with low socioeconomic status experience higher levels of anxiety and depression. Older carers have poorer health status and are reliant on more health and welfare services (Pinquart & Sörensen, 2007; Rosness, Mjørud, & Engedal, 2011), but they have better quality of life, and find caregiving more rewarding and less burdensome than younger carers (Raschick & Ingersoll-Dayton, 2004). This may be because caregiving is more common for older, compared to younger people, who have more competing demands such as workload and childrearing

commitments (Ablett & Jones, 2007; Scharlach, 1994). The following sections summarise other factors that influence the experience of caregiving.

2.3 Caregiver burden

Caregiving places physical, psychological, social and financial demands on informal carers. Caregiver burden refers to the multi-dimensional and subjective response to these stressors (Kasuya, Polgar-Bailey, & Takeuchi, 2000; Windle & Bennett, 2011). The caregiver burden literature is extensive. In the previous section we showed that demographic characteristics contribute to caregiver burden. The majority of work focuses on the physical and psychological consequences of caregiving (Pinquart & Sörensen, 2003[a]; Pinquart & Sörensen, 2007; Sörensen, Pinquart, & Duberstein, 2002). Compared to non-carers, carers are at increased risk of stress and depressive symptoms (Joling et al., 2010; Pinquart & Sörensen, 2003[b]; Shah & Wadoo, 2010), and have lower levels of subjective wellbeing, self-efficacy (Pinquart & Sörensen, 2003[b]) and physical health (Carers UK, 2015; Vitaliano, Zhang, & Scanlan, 2003).

2.3.1 Spousal versus parental caregiver burden

Caring for an ill spouse presents different challenges than caring for an ill parent (Schänzle-Geiger, 2011). Pinquart and Sörensen conducted two meta-analyses; the first on caregiver burden and depression (2003[a]), the second on caregiver physical health (2007). In line with carer demographics, each focused on and compared spousal with parental carers. Pinquart and Sörensen (2003[a]) found strong associations between caregiver burden and depression and behaviour problems of the care recipient. Behaviour problems were defined as

disruptive and aggressive behaviour typically seen in dementia. Increased amount of care provision was associated with reduced uplifts, including: caregiving satisfaction; enjoyment; and closeness. They found that spouses experienced more burden from physical impairment, behaviour problems of the care recipient and longer duration of care than parental carers. The authors explain that spouses may be compromised by chronic age-related illness, whereas parental carer demands may be moderated by their alternative 'distractor' roles and social activities outside the home.

Surprisingly the opposite pattern was true when considering physical health; spousal carers had better physical health than parental carers (Pinquart & Sörensen, 2007). Increased age, lower socioeconomic status and lower levels of informal support were associated with poorer physical health. The authors suggest that spousal carers are typically older than parental carers and so could be relatively more accustomed to failing health. Alternatively, it could be explained by elite sampling; only physically healthy spouses take up the caregiving role. The literature has shown that caregiving stressors have differential effects on spousal and parental carers; spousal carers are more burdened by caregiving but have better physical health than parental carers. Physical health could moderate the effect of caregiving stressors on burden in spousal carers, such that spouses with better physical health experience less burden and depressive symptoms than spouses with poorer physical health.

Both meta-analyses focused on informal carers of older adults; neither distinguished between different care recipient conditions. This is problematic because certain care recipient conditions are more burdensome than others.

The literature has shown that carers are more at risk of stress and depressive symptoms than non-carers (Joling et al., 2010; Pinquart & Sörensen, 2003[b]), but the following section shows that some carers are more burdened than other carers.

2.4 Dementia caregiver burden

In order to understand the burden associated with dementia care it is first important to define dementia. The World Health Organization (2016) define dementia thus:

> "A progressive syndrome in which there is deterioration in cognitive function beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation" (p. 1).

There are an estimated 800,000 people currently living with dementia in the UK. This figure is projected to exceed one million by 2025, and two million by 2051 (Alzheimer's Society, 2014). Approximately 10% of all informal carers living in the UK care for someone with dementia (NHS, 2010); this equates to nearly 700,000 dementia carers (Alzheimer's Society, 2014).

2.4.1 Dementia versus non-dementia caregiver burden

Dementia care is uniquely stressful (Lévesque, Ducharme, & Lachance, 1999; McCurry, 2008; Potgieter, Heyns, & Lens, 2012). Potgieter et al. (2012) describe a number of characteristics that may contribute to the unique stress of

dementia care. First, dementia care is characterised by the continuous, intense and unpredictable nature of stressors, particularly the high levels of cognitive impairment and behaviour problems (Pinquart & Sörensen, 2003[a]). Second, the extended course of the disease; dementia can progress for up to around ten years (Alzheimer's Society, 2013). Research shows that dementia carers are significantly more stressed than non-dementia carers (Bertrand, Fredman, & Saczynski, 2006), and this stress is associated with poorer physical and psychological health (Pinquart & Sörensen, 2007). In a meta-analysis comparing carers and non-carers on different aspects of psychological and physical health, Pinquart and Sörensen (2003[b]) found that dementia carers are more depressed and have lower levels of self-efficacy and subjective wellbeing than non-dementia carers. Specifically, dementia caregiver burden has been associated with depression, poor physical health and reduced quality of life (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006).

2.4.2 Spousal dementia care

In the previous section we showed that caregiving stressors have differential effects on spousal and parental carers. The quality of the pre-dementia relationship between parental carers and their parents, and spousal carers and their spouses, influences both caregiver burden and satisfaction with the post-dementia relationship (Quinn, Clare, & Woods, 2009). In a comprehensive literature review, Etters et al. (2008) found that spousal carers are more burdened by dementia caregiving than other family members. They note that closer relationship ties are associated with increased burden, which may be further exacerbated in spousal dementia care. Spousal carers often have their

own health conditions, and may share reciprocal, fluctuating caring roles with their spouse (Morbey, 2015). In a qualitative study, Murray, Schneider, Banerjee and Mann (1999) found that spousal dementia carers expressed difficulties with loss of companionship and reciprocity. This was a result of their spouse's growing dependency and diminished quality of communication (Quinn, Clare, Pearce, & Dijkuizen, 2008; Stuart-Hamilton, 2000). In a study of dementia carers, Braun, Mura, Peter-Wight, Hornung and Schulz (2010) found that carers whose husbands used more positive communication, such as humour, reported less depression and distress, especially when reciprocated by the carer. Pinquart and Sörensen (2004) found that carers with a closer relationship to the care recipient enjoyed greater subjective wellbeing and fewer depressive symptoms.

So far the literature has shown that spousal carers have better physical health than parental carers (Pinquart & Sörensen, 2007), but they are likely to be more burdened and depressed (Pinquart & Sörensen, 2003[a]), which is particularly marked among dementia carers (Etters et al., 2008). Spousal dementia carers who perceive loss of relationship function are likely to be more burdened than those who maintain function through the provision and receipt of support and positive communication patterns (Braun et al. 2010). Spousal dementia care is unique and important to consider.

2.5 Reducing caregiver burden

Caregiving is burdensome but carers are not a homogeneous group (Bertrand et al., 2006; Pickard, 2004); there are individual differences in response to stressors. For example, longitudinal research shows reported stability or lower

rates of burden and depression in dementia (Gaugler, Davey, Pearlin, & Zarit, 2000) and non-dementia carers (Hilgeman, Allen, DeCoster, & Burgio, 2007). In her pioneering work on stress coping, Folkman (1997) established that positive psychological states coexisted with negative psychological states throughout caregiving and bereavement. These positive states are "benefits or rewards, whether intrinsic (e.g. emotional, cognitive, behavioural) or extrinsic (e.g. interpersonal), that carers obtain from the caregiving experience" (Cheng, Mak, Lau, Ng, & Lam, 2016, p. 452). They are important because they can help sustain the motivation to provide care (Folkman, 1997). Focusing exclusively on burden overlooks positive experiences. Indeed, relatively little work examines the positive features of caregiving that may explain these outcomes (Carbonneau, Caron, & Desrosiers, 2010). Therefore, the following section will draw on both general caregiving and dementia caregiving literatures.

2.5.1 Positive features of caregiving

Research shows that caregiver burden and depression are inversely associated with uplifts, including: satisfaction; enjoyment; and closeness (Pinquart & Sörensen, 2003[a]), and positive cognitions, such as: optimism; self-esteem (Zauszniewski, Bekhet, & Suresky, 2009); sense of fulfilment; and obligation (Cohen, Colantonio, & Vernich, 2002). Folkman (2008) highlights a number of coping processes which give rise to positive emotions, including: benefit finding; adaptive goal processes; reordering priorities and infusing ordinary events with positive meaning. Older adults may be more likely than younger adults to derive positive meaning from caregiving; this has been termed the age-related positivity effect (Carstensen & Mikels, 2005; Mather & Carstensen,

2005; Reed, Chan, & Mikels, 2014). This may be explained in terms of adaptive goals and reordering of priorities; both of which form the basis of Carstensen's (2006) socioemotional selectivity theory (SES). The theory posits that time horizons shorten as people age, and so older adults prioritise emotional gratification over gaining knowledge, and present- over future-oriented goals (Reed et al., 2014). To our knowledge the latter theories have not been examined under caregiving conditions.

Many argue that these positive features are not opposite from burden, but separate aspects of the caregiving experience (Boerner, Horowitz, & Schulz, 2004; Folkman, 2008). There is evidence of a mediating effect of positive cognitions on the relationship between caregiver burden and resourcefulness in dementia carers (Bekhet, 2013). Raschick and Ingersol-Dayton (2004) found that caregiving is more rewarding for spousal than parental carers. As shown before, positive communication, including rapport and humour, are important in the context of spousal care (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001; Quinn et al., 2008).

Researchers have attempted to conceptualise the positive features of dementia care. Carbonneau et al. (2010) developed a conceptual framework which comprised: quality of the caregiver/recipient relationship; meaning of the role; and feeling of accomplishment. The framework posits that carers with high self-efficacy are more likely to pursue enrichment events which enhance the positive aspects. Self-efficacy has been associated with reduced burden (Etters et al., 2008) and greater positive caregiving appraisals in dementia carers, such as: feeling useful; appreciated; and finding meaning (Semiatin & O'Connor, 2012).

So far the literature has shown that carers possess a range of personal characteristics that can buffer the negative impact of stressors on carers' mental and physical health (Carbonneau et al., 2010). However, this does not take account of interpersonal aspects of caregiving. More recently, Cheng et al. (2016) conducted a qualitative study in which dementia carers provided diary recordings of positive gains over an eight-week period. A number of intrinsic themes emerged, including: insight; acceptance; humour; and a sense of purpose and commitment. Some themes emerged that related to the care recipient, such as: gratification and mastery; and developing a closer relationship with the care recipient. The remaining themes involved interpersonal aspects of the role, including: finding support; and feeling useful in helping other carers. The findings suggest that carers do not exist in isolation; they interact with others and utilise informal and formal support systems (Wiles, Wild, Kerse, & Allen, 2012).

2.5.2 Informal carer support

Social networks are defined as: "the structural character of social relationships, such as the number of contacts we have or how often we spend time with those people" (Soulsby & Bennett, 2015: p. 110). Larger social networks are associated with increased subjective wellbeing in older adults (Walsh, 2012), and social participation in the local community can alleviate stress and facilitate emotional support in dementia carers (Milne, Hatzidimitririadou, & Wiseman (2007). Social support is defined as: "a transactional process whereby our relationships provide a platform for the exchange of emotional and practical support" (Soulsby & Bennett, 2015: p. 110). Both emotional and practical

support are critical needs of carers, but the former is often secondary to the latter (Morbey, 2015). Carers tend to emphasise mostly emotional support from family and friends, but not other types of support (Cheng et al., 2016). The function of support varies depending on the population under investigation. For example, Ellwardt, Aartsen, Deeg and Steverink (2013) found that emotional support predicts cognitive functioning in older adults more than practical support. Han et al. (2014) found that affectionate support and positive social interaction specifically reduce psychological burden and the prevalence of major depressive disorder in dementia carers.

It is unclear whether the structure or function of support best captures the heterogeneity of carers (Roth, Mittelman, Clay, Madan, & Haley, 2005). Pinquart and Sörensen (2000) conducted a meta-analysis on subjective wellbeing in older adults. They found that the quality of social contacts predicts subjective wellbeing more than the quantity of contacts, but this varies by support provider. For example, subjective wellbeing is highest in older adults with emotionally-close relationships with relatives, and frequent contact with friends. The authors explain that relatives are structurally determined, and seeing them regularly is likely to involve negative social exchanges in response to increasing care demands. Unlike relatives, friends are selected and share cohort experiences; they are associated with the 'good old times'. This is in line with the widely cited concept of 'intimacy at a distance' (Rosenmayr, 1983); older carers perceive their family relationships as important but wish to remain independent from them. Living alone but in proximity to adult children allows frequent but controlled contact; this is considered ideal for older adults (Erkert, 1992).

The association between support and subjective wellbeing may be mediated by positive perceptions of support, such as level of satisfaction (Ellwardt et al., 2013); it is not the actual number of support providers that reduces or buffers burden, but the perception of that support (O'Rourke & Tuokko, 2000). In a study of spousal dementia carers, Roth et al. (2005) found that increased satisfaction with their social support network mediated the impact of a support intervention on caregiver depression. Carer's satisfaction with formal support is as important as satisfaction with informal support networks. It is important to consider formal support networks in more detail.

2.5.3 Formal carer support

Formal carers are defined as paid health and social care staff in care homes, hospitals and at home (Alzheimer's Society, 2016). Carers and care recipients receive formal care from a range of health and social care services. Pickard (2004) conducted a review of the effectiveness of support and services to informal carers. She found that institutional respite care, day-care and home-help services were associated with reduced carer stress and burden, and delayed institutionalisation. This suggests that the most effective services are those that reduce the objective level of stressors.

Research shows that participation in carer support groups can reduce psychological distress, depressive mood and burden (Han et al., 2014). A qualitative study by Arskey et al. (2002) identified a number of positive aspects of support group involvement, including: emotional support; shared experience; and developing a positive outlook. According to Seddon et al. (2009), carers benefit most from services that encourage them to remain socially active and

maintain healthy living. However, these services do not necessarily facilitate positive outcomes for the carer. Milligan and Morbey (2013) conducted a qualitative study of older male carers. They found that the support needs of older carers providing at-home palliative care could go unrecognised and unmet, and recommend that support services should be more accessible, appropriately timed and affordable.

Social policy for carers is important because it shapes the provision of carer services (Pickard, 2004). It removes barriers to essential services, creating the necessary conditions for carers to adapt to their role. Historically there was an assumption that policy should focus primarily on support services for disabled and older people, and less on carers (Pickard, 2004). Social policy for carers has focused on the continuation of caregiving and sustaining the wellbeing of carers (Pickard, 2001). In 1995, the Carers (Recognition and Services) Act was passed, establishing carers' rights to an assessment of their ability to provide care (Arskey et al., 2002). Carer assessment is problematic for many practitioners and carers. Seddon et al. (2006) conducted a synthesis of qualitative and quantitative research on carer assessment between 1993 and 2006. They found that some practitioners are reluctant to administer assessments, fearing that they will identify excessive needs, or because they perceive a lack of time to administer assessment. According to Seddon and Robinson (2015), practitioners report that carer assessments are practical and problem-focused, and do not routinely explore the rewarding aspects of caregiving, such as: sense of purpose; new perspective on life; feeling valued; and acquiring new skills. By understanding these aspects, practitioners would understand carer wellbeing, commitment to continued caregiving and the

dynamics of caring relationships. This is consistent with the aforementioned social policy aims for carers.

Seddon et al. (2006) found that there was a discrepancy between carer service requests and assessment outcomes. In England, they found that 37% of assessments granted support with domestic activities, but much less attention was paid to psychosocial and interpersonal aspects, with only 3% granted emotional support. In Wales, over half of carer's requests for flexible in-home respite care and counselling support were not being granted by carer assessments (Seddon et al., 2006). The English and Welsh figures are similar throughout the review (Windle & Bennett, 2011). As shown earlier, emotional support is as critical as practical support (Morbey, 2015), and yet assessment outcomes are largely practical. This can lead some carers to hold few expectations of assessment and present modest service requests (Windle & Bennett, 2011). There may be a gap between carer assessment policy and practice. Morbey (2015) recommends multi-sphere carer assessment that also accounts for the care recipient's health and support circumstances.

Since the 1995 Carers (Recognition and Services) Act, there has been a dramatic increase in strategy and legislation for supporting carers in the UK (Windle & Bennett, 2011). The Department of Health (1999) published 'Caring about carers: A National Strategy for Carers', consisting of three key elements: information; support; and care. The 2004 Carer's Equal Opportunities Act ensured that carers received support beyond their role (Seddon et al., 2006). The National Strategy for Carers policy was reviewed in 2010, to include: involving carers in designing local care provision; planning individual care packages; and enabling carers to fulfil their educational and employment

potential. More recently, The Care Act 2014 was introduced to replace most previous carer policy. In England, it made specific recommendations on who should be conducting carer assessments, and how support eligibility is determined. It emphasised access to and funding for residential and community care, and for specific services such as respite care (Carers UK, 2015). More research is needed which recognises that carers are experts in care and also that they have important commitments beyond the caregiving role.

The informal and formal support literature is predicated on the assumption that all carers are burdened and vulnerable. We have shown that this is not always the case; carer's needs are wide-ranging, varied, and often fluctuating (Morbey, 2015). Bennett (2015[a]) distinguishes between services and interventions; services should be accessible for all, but intervention is only necessary for the minority when burden is too high, for example: carers who need support without knowing it.

There have been two key meta-analyses in this area, the first on carer interventions (Sörensen et al., 2002) and the second on dementia carer interventions (Pinquart & Sörensen, 2006). Both analysed the efficacy of several interventions on caregiver burden, depressive symptoms, subjective wellbeing, ability/knowledge, care recipient outcomes and institutionalisation. In general, both studies found that interventions led to small improvements in most outcomes. Sörensen et al. (2002) identified a number of factors that moderated the effectiveness of interventions. Interventions were relatively less effective for spousal carers, male carers, younger carers and dementia carers on most outcome variables. Group interventions were less effective at improving burden and wellbeing than individual interventions. For both studies, the majority of

intervention effects were domain-specific; for example, the effects of cognitive behaviour therapy were specific to burden and depressive symptoms in dementia carers (Pinquart & Sörensen, 2006). This suggests that one approach does not fit all outcomes and that interventions need to be tailored to the specific needs of carers. Bennett (2015[a]) argues that there is no 'one-size-fits-all' solution for support services. Although there have been recent positive developments in specific carer services (Department of Health, 2010), Bennett recommends that practitioners and policy makers provide more personalised services that are easily accessible.

Timing of intervention is important. In a study of older widowers, Bennett (2010) notes that support offered too early can be ignored, and support offered too late may have negative consequences. There may be a gap between actual need and perception of need. Milligan and Morbey (2013) found that some older male carers can find it difficult to acknowledge emotional aspects of their role. This is problematic; as we saw with carer assessment, practitioners tend to focus on practical over emotional support needs (Morbey, 2015). Thus, for example, men's emotional needs may be overlooked. According to Bennett (2015[a]), service practitioners and policy makers should acknowledge the heterogeneity of carers and provide personalised services and timely interventions that match actual and perceived need.

So far the literature has shown that caregiving is burdensome, but carers respond differently to this adversity. Not everyone is affected by burden in the same way (Rutter, 2012). Some carers are entirely burdened and others less so. Some carers find caregiving life-enhancing. Research needs to reconcile the

heterogeneity between disorder and wellbeing in carers; resilience may be the answer (Ungar, 2012).

2.6 Defining resilience

Resilience research has been growing substantially (Luthar, 2006). The study of risk and resilience has its roots in developmental psychopathology (Windle, 2011). Early work examined resilience in relation to stress-resistant children and adolescents (Garmezy, 1985; Liebenberg & Ungar, 2009). These studies were based on definitions of resilience as the process of overcoming stress or adversity (Luthar, Cicchetti, & Becker, 2000). Over time researchers began to argue that resilience is not simply stress resistance or invulnerability to stress, but the ability to function positively and recover from setbacks more quickly than others with an equivalent level of exposure to negative events (Dias et al., 2015; Rutter, 1995; Rutter, 2012). An implication of this is that research should compare carers with other carers and not compare across different adversities. According to Liebenberg and Ungar (2009), resilience warrants its own discussion, away from vulnerability and risk. Subsequent definitions have not distinguished between resilience process and outcome or identified the main conceptual mechanism of resilience.

Windle (2011), in collaboration with the Resilience and Healthy Ageing Network (http://resilience/bangor.ac.uk), conducted a comprehensive concept analysis of resilience, drawing on a range of multi-disciplinary perspectives. She defined resilience thus:

> "The process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual,

> their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity" (p. 163).

Windle's (2011) definition identifies three key features of resilience: significant adversity or risk; protective assets and resources to offset the effects of adversity; and positive adaptation or avoidance of negative outcomes. The previous sections showed that spousal dementia caregiving is an adversity for many carers. Joling et al. (2015[a]) conducted a Delphi consensus study to address the essential components of resilience for dementia carers, consulting a multi-disciplinary panel of informal carers and professionals with relevant experience. Dementia carers believed that receiving little social support from family and friends and having few social activities best represented carer adversity. Professionals believed that adversity was best represented by care recipient behavioural problems. The panel agreed that agitated and aggressive behaviour was most stressful. The nature of adversity is important when defining resilience; maintenance of normal functioning may characterise resilience under conditions of severe adversity whereas better than expected functioning may be required under less severe conditions (Windle, 2011).

Joling et al. (2015[a]) also provided definitions of carer resilience. Dementia carers and professionals agreed that resilience comprises individual factors such as coping and flexibility, and interpersonal factors such as the carer having a good relationship with the care recipient. However, there were a number of important differences. For instance, carers defined resilience as a dynamic process whereas professionals defined it as a positive outcome in response to adverse circumstances. Health was emphasised by professionals but not by carers. Overall, the consensus was that dementia carer resilience is

"feeling competent to provide care as a carer, while facing substantial behavioural problems in the person with dementia" (p. 6). Whilst it is advantageous that this definition is based on carer and professional consensus, it is limited to just one carer adversity and does not account for aspects other than competence. The definitional discrepancy between those practically involved in caregiving reflects resilience theory. Resilience is difficult to define; it is conceptually 'fuzzy' and inconsistently operationalised (Lerner, 2006; Ungar, 2003). There are a number of theoretical approaches to resilience: resilience factors and resilience as a process or outcome.

2.6.1 Psychological resilience

Traditionally resilience has been examined on an individual level, emphasising psychological attributes and trait aspects (Bonanno, Galea, Bucciarelli, & Vlahov, 2007; Kalisch, Müller, & Tüscher, 2015; Windle, Woods, & Markland, 2010). This is in line with the shared definitions of dementia carers and professionals in the Delphi consensus study (Joling et al., 2015[a]). Masten, Best and Garmezy (1990) defined psychological resilience in terms of internal states of wellbeing and effective functioning in the environment. Rutter (1987) described a number of psychological qualities held by resilient individuals, including self-efficacy, self-esteem and a range of problem solving skills. Windle, Markland and Woods (2008) put forward a theoretical model of psychological resilience comprising competence, self-esteem and interpersonal control. They view psychological resilience as a developmental process, whereby positive psychological resources protect individuals in the face of adversity. However, these are not likely to be the only factors associated with psychological

resilience. Researchers have examined resilience in relation to: optimism; acceptance; emotional intelligence; and mastery (Carbonneau et al., 2010; Cherry et al., 2013; Deist & Greeff, 2015; Gaugler, Kane, & Newcomer, 2007; Koole, Schwager, & Rothermund, 2015). Conceptual overlap between these constructs has led to definitional difficulty (Cherry et al., 2013).

Psychological resilience generally assumes that resilience is fixed, and that resilient traits, or resilience factors (Kalisch et al., 2015), directly influence outcomes (Masten, 1999). Spahni, Morselli, Perrig-Chiello and Bennett (2015) used a latent profile analysis to identify patterns of adaptation to bereavement in older spouses. They identified three groups: resilients; copers; and vulnerables. Psychological resilience was one of the most important variables for group allocation. This suggests that psychological resilience can contribute to, but is distinct from, resilience as an outcome (Mancini & Bonanno, 2009). However, Kalisch et al. (2015) emphasise that this is not a causal association; we cannot reliably predict a resilient outcome from psychological resilience. Whilst it may seem circular that the trait of resilience contributes to the outcome of resilience, psychological resilience is neither necessary nor sufficient for resilience (Bennett, 2015[b]).

So far the literature has shown that resilience factors are typically explained in terms of burden rather than resilience. This may be exacerbated by conceptual overlap, particularly in the psychological resilience literature. More research is needed to assess the mechanisms through which these resilience factors influence carer outcomes (Cherry et al., 2013).

2.7 Resilience process versus resilient outcome

There is some debate about whether resilience is best understood as a dynamic process or unitary outcome (Bennett, 2015[b]; Liebenberg & Ungar, 2009; Spahni et al., 2015; Windle et al., 2010). Kalisch et al. (2015) distinguish between resilience as a process or outcome and resilience factors, which are variables that predict a resilient outcome. Resilience has been viewed as a dynamic process that unfolds over time in response to stress (Bonanno & Diminich, 2013). It has also been viewed as an outcome, typically a positive response to a stressful event (Masten, 2001; Windle et al., 2010).

The resilience process follows a trajectory of stable mental health during and after a traumatising event or prolonged period of adversity (Mancini & Bonanno, 2009). Based on the work of Bonanno (2004) and Moore and Stratton (2003), Bennett (2010) found that not all older widowers were resilient immediately after bereavement. Some men become resilient gradually, some following a turning point and others experience gradual change and turning points. This suggests that the developmental trajectory of resilience is as important to consider as its component parts. According to Rutter (2012), exposure to adversity can either increase vulnerability through a sensitisation effect, or decrease vulnerability through a steeling effect. Steeling effects occur after intermittent exposure to brief periods of stress which then increases resistance to later stresses. Unfortunately, little research has examined steeling effects in relation to psychosocial stressors, such as caregiving.

This conceptual debate extends to the context of dementia care. For carers, the aforementioned turning points may represent care status transitions, for example; institutionalisation or widowhood. Steeling effects may

represent previous caregiving experiences or consecutive care status transitions. The unpredictable course and extended duration of dementia makes it particularly unclear whether resilience is an outcome or a process (Potgieter et al., 2012); carer resilience is a 'moving target' (McCurry, 2006). Drawing on early work in the field of psychotherapy, resilience can be viewed as a change process (Greenberg, 1986). That is, a chain of suboutcomes that are linked together on a pathway toward one ultimate outcome (Safran et al., 1988). This conceptualisation fits with dementia care; resilience is ultimately an outcome that dementia carers can achieve, but is comprised of a number of intermediate suboutcomes which represent the process of overcoming care challenges (Kalisch et al., 2015). Carers can achieve increasing amounts of resilience in response to further challenges over time (Bennett, 2015[b]).

On the balance of the evidence, we argue that resilience is an outcome following a highly stressful event and there are a number of resilience factors that promote or detract from that outcome (Mancini & Bonanno, 2009). Resilience process refers to any mechanism by which a resilient outcome is achieved, including developmental trajectories and transitions (Kalisch et al., 2015).

2.7.1 Resilience measurement

There is currently no 'gold standard' measure of resilience (Joling et al., 2015[a]; Lerner, 2006). Traditionally, resilience has been studied using quantitative research methods; for example, measures originally meant for screening mental health (Liebenberg & Ungar, 2009). Resilience research is not being translated into useful resilience measurement tools (Gartland, Bond, Olsson, Buzwell, &

Sawyer, 2011). This means that researchers and practitioners may struggle to make an informed choice on the most appropriate scale for their chosen population and context (Windle, Bennett, & Noyes, 2011). The latter authors conducted a methodological systematic review of resilience measurement scales. They found that many resilience scales lacked conceptual and theoretical adequacy and required further validation work. However, they identified three scales with equally good psychometric properties: the Connor-Davidson Resilience Scale (CD-RISC); the Resilience Scale for Adults (RSA); and the Brief Resilience Scale. Interestingly, they reflect the aforementioned conceptual debate (Windle, 2011). The CD-RISC was designed to measure stress coping ability, with four out of five of its factors individual-level. The RSA was designed to measure the intra- and interpersonal protective factors that facilitate adaptation to psychosocial adversities. The Brief Resilience Scale was designed to measure resilience as an outcome; the ability to bounce back or recover from stress. According to Windle (2011), the majority of resilience self-report scales measure individual-level psychological resilience.

Resilience tends to be measured indirectly, being assumed more as a hypothetical construct (Windle et al., 2008). For instance, it has been operationalised using proxy measures of low/high functioning; for example, few or no depressive symptoms (Galatzer-Levy & Bonanno, 2012; Hardy, Concato, & Gill, 2004); and high life satisfaction (Chappell & Dujela, 2008). However, one of the defining attributes of resilience is adversity (Windle, 2011); individuals cannot be resilient in conditions of no or low adversity (Bennett, 2015[b]). Adversity may include short-term or long-term social or physical stressors (Kalisch et al., 2015). In this sense resilience is different from other concepts

such as wellbeing and positive features, where individuals may thrive in the absence of risk factors (Windle, 2011).

A standard method of operationalising resilience is to use proxy measures of low/high functioning against a measure of low/high adversity or risk (Masten, 2001; Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2015). Studies have generally classified resilient individuals as having high quality of life in the presence of health-related or psychosocial adversity (Hildon, Montgomery, Blane, Wiggins, & Netuveli, 2010); and little or no disorder following a traumatic experience (Bonanno, Galea, Bucciarelli, & Vlahov, 2006). Caregiving studies have operationalised resilient individuals as having low perceived burden in the face of frequent care demands (Gaugler et al., 2007); and low levels of distress in the face of caring for a relative with severe dementia (Joling et al., 2015[b]). Unfortunately, proxy measures of high functioning do not necessarily equate with resilience. These outcomes overlook the characteristics and processes that contribute to resilience (Windle et al., 2010).

Masten (2001) described two main approaches to the study of resilience: person and variable focused. The person focused approach aims to identify groups of individuals who show similar patterns of resilience in order to characterise contributing factors. This approach is often used to classify people as resilient or not using multiple criteria (Windle, 2011). Researchers have classified resilient widowers as meeting each of the following criteria (Bennett, 2010; Moore & Stratton, 2003):

i. View their current life positively.

ii. Currently actively participating in life.

iii. Return to a life that had meaning and satisfaction.

iv. Coping with no sign of distress.

Unlike the previous method of operationalising resilience, these criteria do not rely on proxy measures, and identify resilient individuals and the characteristics that contribute to this outcome. In these studies, the adversity was widowhood, but it could apply to dementia caregiving (Joling et al., 2015[b]). Unfortunately, we are unaware of any resilience criteria specific to carers. Classifying individuals as resilient or not assumes that resilience is a binary outcome. However, Spahni et al. (2015) identified three latent profiles of bereavement in older adults: resilients; copers; and vulnerables. This suggests that resilience is distinct from coping (Iparraguirre, 2015); there may be a middle group of people who do not meet all resilience criteria. There is a lack of clarity on how this middle group should be conceptualised. The work of Spahni et al. was published after data collection and publication of our first paper, in which we classified participants as resilient or not. Therefore, for the purposes of this thesis we proceed on the basis that resilience is a binary outcome, and then return to it in the general discussion.

2.7.2 Mechanisms of resilience

The second of Masten's (2001) approaches, the variable focused approach, explains the process of resilience; that is, the underlying protective factors and mechanisms that moderate the impact of adversity on resilient outcomes (Hjemdal, Friborg, Stiles, Rosenvinge, & Martinussen, 2006; Koole et al., 2015; Windle, 2011). For example, an individual with high psychological resilience

may be more likely to achieve a resilient outcome because their psychological resilience predisposes them to cope with stressors in a positive way. Positive coping would be the resilience mechanism in this example (Kalisch et al., 2015). However, it is important to note that these processes should not be grouped together without distinction (Rutter, 2012).

Individual-level processes contribute to resilient outcomes. Research shows that psychological resilience buffers adversity, leading to positive adaptive outcomes (Rutter, 1987). For example, Windle et al. (2010) found that psychological resilience moderates the relationship between ill-health and subjective wellbeing in those aged 60 and over, but not in those aged 50-59, and the effect weakens with age. They conclude that psychological resilience may protect individuals from stressors such as failing health. The findings fit within a lifespan developmental framework, suggesting that psychological resilience is not fixed but fluctuates over time in response to changing life circumstances (Luthar, 2006). It is important to note that these protective processes moderate both individual vulnerabilities and environmental stressors but may not produce a resilient outcome if the level of adversity is too high (Masten et al., 1990).

Kalisch et al. (2015) put forward a parsimonious theory of resilience, called positive appraisal style (PASTOR). The authors define resilience as "an empirically observable phenomenon, namely that someone does not develop lasting mental health problems although he or she is subject to adversity" (p. 5). Controversially, the theory states that positive appraisals of potentially threatening stimuli represent "the common resilience mechanism onto which all resilience factors converge and through which they exert their protective

effects on mental health" (p. 11). They acknowledge that there are many resilience factors, including individual differences, social dimensions and contextual factors, but argue that the latter socio-environmental factors are 'distant influences'. Positive appraisal of adversity moderates the relationship between all resilience factors and resilient outcomes.

PASTOR has been criticised on a number of grounds. First, Kalisch et al.'s definition of resilience may be too narrow and does not consider the assets and resources that individuals utilise to facilitate resilience (Kimbrel & Beckham, 2015). Second, positive appraisal may actually compromise resilience if it leads to underestimation of risk and overestimation of ability (Schneider, 2001). Individuals may need to take direct action to change the stressor in some contexts. Finally, the notion of a single individual-level resilience mechanism may be too reductionist. According to Ungar (2015), PASTOR ignores the fact that individuals interact with other protective factors, such as family, community and cultural factors, which may also moderate the influence of stress on resilience. Individual-level factors, whilst important, are strongly influenced by socio-environmental factors in determining resilience (Bennett & Windle, 2015).

2.8 Factors associated with carer resilience

Factors associated with carer resilience are not fully understood; they are often studied indirectly in terms of burden (Cherry et al., 2013). Informed by Windle (2011), Cherry et al. (2013) identified a framework of three interrelated factors influencing resilience in dementia carers: psychological factors; social and cultural factors; and properties of the care relationship. This section will briefly

summarise some key psychological and socio-demographic resilience factors. Properties of the care relationship will be discussed later.

2.8.1 Individual-level factors

To our knowledge, most studies on psychological resilience focus on older adults generally, and less on older carers. Dementia carer studies tend to conceptualise resilience as a trait predictor of clinical outcomes, such as depressive symptoms (O'Rourke et al., 2010), or a predictor of transitions from dementia care, including institutionalisation, care recipient death and loss to follow-up (Gaugler et al., 2007). In a study of spousal dementia carers, O'Rourke et al. (2010) examined three facets of psychological resilience, perceived control, commitment to living and challenge versus stability, as predictors of depressive symptoms over time. They found that increased baseline control and challenge predicted lower levels of depressive symptoms at one-year follow-up. Commitment to living with not associated with depressive symptoms over time. No single resilience factor has predominated, and psychological resilience as a trait has been criticised as it implies that a person who does not have this attribute is a failure (Windle, 2011).

Cherry et al. (2013) identify key psychological traits that are associated with carer resilience, including hardiness and sense of coherence. Hardiness comprises three psychological attributes: commitment; challenge; and control. Interestingly, studies have operationalised psychological resilience using these factors (O'Rourke et al., 2010). Both hardiness and resilience have been examined as moderators of stress and psychopathology (Windle, 2011); both are associated with positive perceptions of caregiving (Cherry et al., 2013).

However, Windle (2011) distinguishes between them; hardiness is stable whereas resilience is dynamic and changes in response to stressors across the lifespan. Like hardiness, sense of coherence consists of three components: a sense that life is comprehensible; manageable; and meaningful. Cherry et al. (2013) suggests that meaning-making is the most important feature for dementia carers. They find meaning by using past experiences, cultural values and norms to interpret and appraise caregiving challenges and stay positive in their role (Rubenstein, 1989).

Socio-demographic factors contribute to resilience in carers, but the evidence is inconclusive. Some studies show that women make more resilient carers (Gaugler et al., 2007; Netuveli, Wiggins, Montgomery, Hildon, & Blane, 2008), whereas others find the reverse (Fuller-Iglesias, Sellars, & Antonucci, 2008). However, there are more studies examining resilience in women than men (Bennett, 2015[b]). Cherry et al. (2013) note that resilience researchers tend to examine gender in terms of sex differences and less in terms of gender role conflict or gender identity (Baker & Robertson, 2008). Studies on carer resilience have largely focused on adults over the age of 65, assuming that carers are relatively homogeneous. However, research shows that resilience fluctuates throughout the lifespan; people are influenced by age differently (Windle et al., 2010). Gaugler et al. (2007) conducted a three-year longitudinal study of dementia carers. They examined the predictive relationship between care context variables, care recipient status and individual, family and community resources and resilience at baseline. Although there was no

association between carer age or gender and resilience, longer care duration was associated with resilience.

Frequency and severity of care recipient behavioural problems negatively influences carer resilience (Cherry et al., 2013). Research shows that carers have limited knowledge about dementia (Schindler, Engel, & Rupprecht, 2012). This is problematic because carer knowledge of the causes, symptoms and prevalence of dementia is associated with reduced depression (Graham, Ballard, & Sham, 1997). The authors suggest that understanding the degenerative course of dementia may explain this anxiety. However, perceived knowledge may be as important as actual medical knowledge. Schindler et al. (2012) found that dementia carers who perceive their knowledge as good had lower burden than those who perceived it as poor. Cherry et al. (2013) suggest that resilient carers may be more likely to perceive that they have sufficient knowledge. Furthermore, they suggest that resilient carers may be more likely to actively seek information whereas non-resilient carers may avoid it.

There is a lack of conclusive research on socioeconomic resources and resilience in carers. Research shows that carers with greater financial and material resources from family members are more likely to become resilient (Monroe & Oliviere, 2007). Many working age carers have no option but to leave employment to become full- or part-time carers. This can have financial consequences which may reduce their ability to become resilient (Carers UK, 2014). Research has failed to establish a reliable association between socioeconomic status and resilience in older adults (Netuveli et al., 2008). Gaugler et al. (2007) found that higher income and education are associated

with lower resilience in dementia carers, but there is no effect of being employed on resilience.

Despite this many carers report stable or better health during caregiving. Studies have shown that resilient dementia carers have better health and wellbeing than non-resilient carers (Petriwskyj et al., 2015; Wilks & Croom, 2008). This suggests that resilience may buffer the impact of caregiving stressors on physical health.

2.8.2 Socio-environmental factors

In the previous section we summarised key psychological and socio-demographic factors associated with carer resilience. Cherry et al.'s (2013) review also included properties of the care relationship, including informal and formal social support. Research shows that larger social networks facilitate resilience and subjective wellbeing (Gaugler et al., 2007; Ross, Holliman, & Dixon, 2003; Walsh, 2012). Gaugler et al. (2007) found that dementia carers who used more informal and formal support were more likely to be resilient. Research shows that social support moderates the effect of stress on carer resilience (Wilks & Croom, 2008). However, some argue that positive perceptions of support, such as level of satisfaction, moderate resilience (Deist & Greeff, 2015). It is unclear whether actual or perceived social support best captures the resilience of carers (Luthar, 2006). Some argue that resilience is not solely determined by the structural composition of social support, but by perceived satisfaction with support (Roth et al., 2005; Sherman, Webster, &

Antonucci, 2013). Social support quality is at least as important as support quantity.

The use of institutional respite care, day-care, home-help services and overnight stays at hospital predict high resilience (Gaugler et al., 2007). Research shows that multi-component dementia carer services, such as respite care and community support groups, can enhance resilience through improved quality of life, wellbeing and self-efficacy (Sörensen, Duberstein, Gill, & Pinquart, 2006). Unfortunately, carers often wait until later in the disease process before using these formal services (Bookwala et al., 2004). Research shows that beliefs and attitudes towards respite care are key determinants of its use for dementia carers (Phillipson, Jones, & Magee, 2010); for example, perceived lack of need and knowledge (Brodaty, Thomson, Thompson, & Fine, 2005). This suggests that there is a discrepancy between availability and utilisation of formal support; formal support facilitates resilience only if it matches perceived need.

Resilience is receiving increasing interest from policy and practice (Windle et al., 2011). There are many carer interventions aimed at a range of outcomes (Petriwskyj et al., 2015). In an earlier section, two meta-analyses showed that carer interventions lead to significant but small improvements on a range of outcomes, including known correlates of resilience such as subjective wellbeing (Pinquart & Sörensen, 2006; Sörensen et al., 2002). However, very few interventions target carer resilience specifically and exclusively (Bennett, 2015[b]; Petriwskyj et al., 2015). In a systematic review of resilience interventions for older adults, Bennett (2015[b]) found that interventions tend to

incorporate resilience as a secondary outcome or as a factor contributing to outcomes such as depression (Bennett, 2015[b]). This can make it difficult to assess the extent to which interventions enhance resilience (Petriwskyj et al., 2015). In line with previous work (Pinquart & Sörensen, 2006; Sörensen et al., 2002), Bennett found that these interventions led to only minor improvements in resilience and depression. To our knowledge, there are currently no interventions targeting resilience in dementia carers.

Intervention works on the assumption that resilience is a process amenable to change, and not a fixed trait (Petriwskyj et al., 2015). A problem with the aforementioned interventions is that they target only individual-level factors. According to Windle (2011), effective carer interventions acknowledge the dynamic interplay between individual-level and socio-environmental resilience factors. Whilst it is important to develop individual strengths, individual-level approaches may place too much responsibility for change solely on the individual (Ungar, 2015; Windle, 2011). Indeed, the notion that resilience factors are fixed, and the focus of interventions on individual-level factors, may explain the weak effect sizes in the above studies.

Carer resilience studies typically focus on personal attributes, and this has resulted in fewer studies on informal and formal support and resilience. As seen with psychological and socio-demographic resilience factors, interpersonal factors tend to be explained in terms of burden (we discussed many of these explanations in sections 2.5.2 and 2.5.3). Researchers argue that resilience is determined by the interaction of individuals and their immediate and wider environments (Bennett & Windle, 2015; Ungar, 2015). More research is needed

to explore how individual-level resilience factors relate to interpersonal resilience factors (Luthar, 2006).

2.9 An ecological approach to resilience

It is clear from the literature that individual-level factors and mechanisms play an important role in facilitating resilient outcomes, but we have also shown that not all resilience factors are individual-level. Indeed, researchers who have focused on psychological dimensions of resilience acknowledge the existence of wider factors (Kalisch et al., 2015). There is a growing trend away from individual-level resilience towards more interpersonal and socio-environmental aspects of resilience (Bennett & Windle, 2015; Liebenberg & Ungar, 2009; Ungar, 2012). According to Windle (2011), people do not exist in isolation; they interact with their social and environmental contexts. This has led some authors to consider the social ecology of resilience (Bonanno et al., 2007; Ungar, 2011).

An ecological approach argues that resilience is a result of internal resources, such as psychological, financial, health resources, and external resources, including informal family and friend support, and formal private, public and voluntary services (Iparraguirre, 2015; Kimbrel & Beckham, 2015). Iparraguirre (2015) analysed ten-year longitudinal data from the English Longitudinal Study of Ageing. He examined the protective influence of financial (e.g. income and housing factors) and health resources (e.g. diagnosed conditions) on a range of adverse life events and outcomes between middle- and old age. Iparraguirre found that resources do not prevent negative outcomes; for example, the onset of disability was associated with reduced

quality of life and physical activity. However, higher financial resources and better health reduced or even completely offset a range of negative outcomes over time. Unfortunately, this study did not examine the protective influence of external resources.

Resilience may reflect the capacity of systems to adapt, rather than the capacity of individuals to overcome challenges (Ungar, 2015). Researchers argue that some individuals cannot be resilient without these wider resources (Bennett & Windle, 2015; Liebenberg & Ungar, 2009; Ungar, 2011; Ungar & Lerner, 2008). Earlier, Windle (2011) defined resilience in terms of "assets and resources within the individual, their life and environment" (p. 163). According to Windle (2011), assets are inherent to the individual, whereas resources are external, including contextual and environmental factors (Windle, 2011). Windle's definition synthesises the aforementioned principles of resilience, and emphasises the full ecology of resilience in caregiving.

Ungar (2015) notes that environmental factors explain as much as, if not more, variance in positive developmental outcomes from adversity than individual factors. This extends to qualitative work. For example, in her work on older widowed men, Bennett (2010) found that resilience required external agency from informal and formal sources; they would not have been able to achieve resilience alone (Ungar, 2012). This suggests that timing and context are important; different factors matter more than others at different times and in different contexts (Bennett, 2010; Ungar, 2015); resources do not protect all people all of the time (Iparraguirre, 2015).

The theoretical basis for resilience clearly acknowledges that protective factors operate across a number of levels and interact with each other (Windle,

2011). Despite this, resilience is typically examined on distinct levels (Masten, 2007); either solely individual or solely social. There is need for a more integrated ecological framework. One example is Bronfenbrenner's (1994) Ecological Systems Theory. The theory posits that people draw on individual characteristics and immediate and wider environmental resources to reduce or prevent chronic adversities leading to psychopathology. Although the theory was originally used to understand child psychopathology, it has since been applied to the gerontology and resilience literatures (Windle, 2011). In the previous sections we showed that a lot of the caregiving literature is individual-centric. Social ecology frameworks that acknowledge the integrated influence of individual, community and societal factors have rarely been applied to caregiving. There is need for a caregiving-specific ecological resilience framework.

In light of this, Windle and Bennett (2011) developed a theoretical model of ecological resilience applied to informal carers, which posits that each carer draws on individual assets, but also on community and societal resources which interact to facilitate or hinder resilience (Figure 2.1). The resources are interactive, non-discrete and non-hierarchical; carers may draw on none, some or all of the resources at any one time. Individual assets include psychological, biological, material resources and health behaviour. They also comprise demographic characteristics such as gender, age, socioeconomic status and ethnicity. Community resources include family relations, social support, social participation, social cohesion and housing factors. Finally, societal resources include social policy, employment, neighbourhood and economic factors, and health and social care services. The absence of assets and resources may lead to

further caring challenges or negative consequences to their wellbeing. This is likely to involve many of the caregiver burden factors that we illustrated in previous sections.

Windle and Bennett's (2011) framework is theoretical so the assets and resources are by no means exhaustive. As we have seen, relatively few studies have focused on carer resilience. As far as we are aware, the framework has been used for theory development (Joling et al., 2015a), but has not yet been tested empirically on carers. It is widely acknowledged that social ecology frameworks are designed to test the dynamic interplay within and across each level (Bronfenbrenner, 1994; Windle, 2011; Windle & Bennett, 2011). However, little research has examined the mechanisms by which adversities and protective assets and resources work (Mancini, 2015; Windle, 2011).

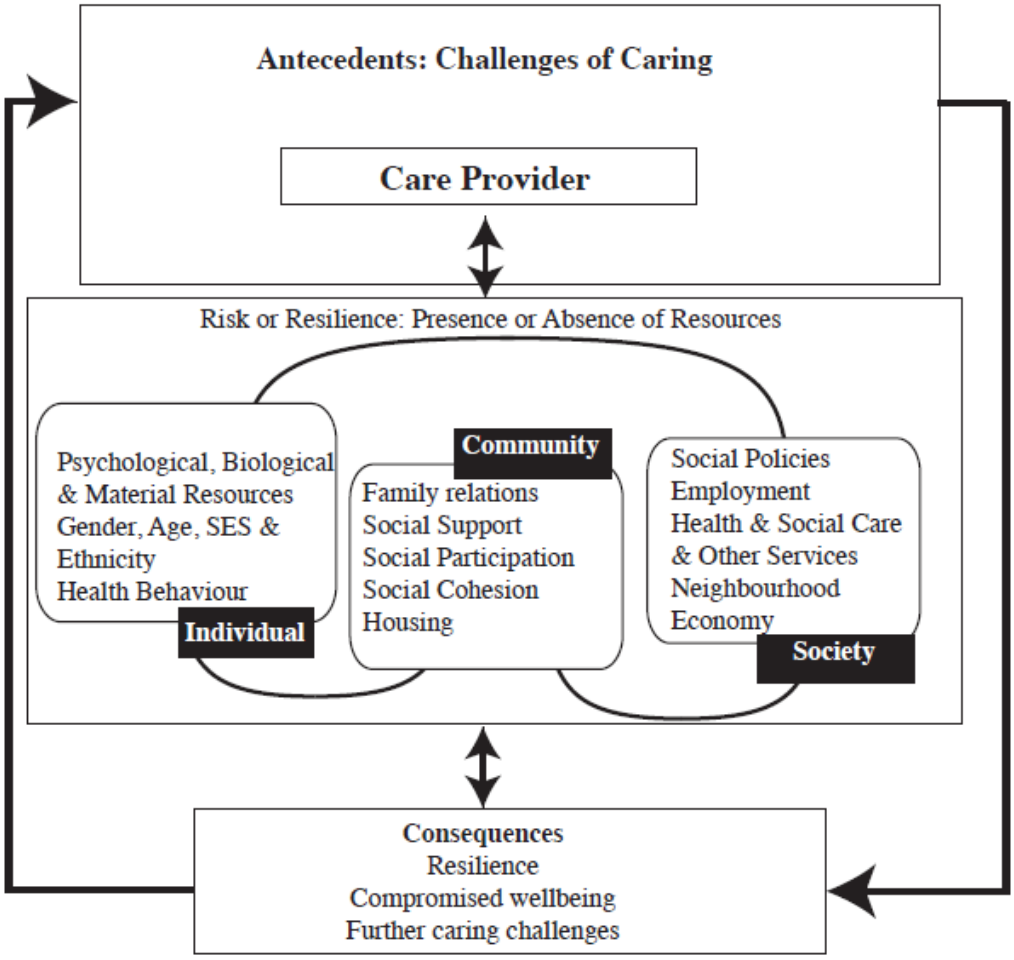

Figure 2.1: The Resilience Framework applied to informal carers (Windle & Bennett, 2011).

2.10 Methodological considerations

As previously discussed, there are two approaches to the study of resilience (Masten, 2001). The variable focused approach employs tightly controlled research designs and statistical techniques to test resilience mechanisms (Potter & Hepburn, 2005). Researchers have used prospective longitudinal models to examine resilience as a protective buffer of negative outcomes, such as depressive symptoms (O'Rourke et al., 2010) and institutionalisation (Gaugler et al., 2007). Others have assessed the moderating influence of resilience on positive adaptive outcomes, such as subjective wellbeing (Windle et al., 2010). While variable focused approaches maximise statistical power and are well suited to searching for links between variables, they can be narrow and fail to capture the complexity of people's lives (Masten, 2001).

The second of Masten's approaches, the person focused approach, compares groups drawn from the same high risk sample (e.g. carers) who have resilient or non-resilient outcomes (Masten, 2001). The purpose is to examine what might account for the differences in outcome. Studies have identified resilient individuals through classification criteria (Bennett, 2010) and proxy measures of high/low functioning against a measure of high/low adversity (Joling et al., 2015[b]). Qualitative research methods are often employed as part of a person focused approach; they allow the researcher to explore resilience factors and processes in great depth at multiple levels over time (Ablett & Jones, 2007; Cheng et al., 2016; Masten, 2001). The following sections describe and evaluate some of the most common qualitative methodological frameworks that can be applied to the area of caregiver resilience (Nicholls, 2017).

2.10.1 Qualitative methodological considerations

Phenomenology is concerned with the subjective lived experience of individuals (Husserl, 1911/1965); it is the phenomenologist's responsibility to capture the individual's interpretation of a particular phenomenon. Phenomenology provides a rich description of human experiences, and its interpretive approach remains close to the raw data (Smith, 2004). However, by focusing on individual perspectives it can miss important precursors, consequences and factors associated with the phenomenon itself (Willig, 2013). Informal caregiving is rarely a solo effort and each carer exists as part of a wider community of carers. Resilience is not just embedded within the individual, but also in the social environment (Bennett & Windle, 2015; Ungar, 2015).

Ethnography examines the things that define us as being part of a particular cultural group, and how members of that group ascribe meaning to everyday life (Griffin & Bengry-Howell, 2008). Ethnographers may attempt to characterise what makes carers carers, and how carers find meaning in their role. Unlike phenomenology, ethnography captures the wider perspective of caregiving, but does not capture the dynamic interactions between individuals within a group. Caregiver resilience operates within and across a number of interactive levels (Luthar, 2006; Windle, 2011; Windle & Bennett, 2011). There is need for an approach which provides an accurate and detailed account that is also sensitive to the ecological and interactive nature of caregiver resilience.

Grounded theory explores meaning through symbolic interactions between people and communities (Glaser & Strauss, 1967). Traditional grounded theory methods begin with no pre-existing theoretical framework;

the aim is to generate inductive theory that is fundamentally grounded in the data (Nicholls, 2017). The grounded theorist begins with a simultaneous process of data collection and analysis in order to identify conceptual themes from open codes and focused categories within each interview; this process is reflexive so that emergent themes build on existing conceptualisations and inform subsequent data collection (Charmaz, 2014). The process ends when the researcher reaches saturation; the point at which no new information or themes are observed (Guest, Bunce, & Johnson, 2006). Grounded theory is popular because it bridges the principles of quantitative and qualitative methods (Denzin & Lincoln, 2005). Its inductive process allows us to explore resilience factors from the bottom up, which is important given the conceptual inconsistency of resilience (Lerner, 2006; Ungar, 2003). Unfortunately, grounded theory has been criticised for failing to acknowledge the researcher's role in constructing and interpreting data (Charmaz, 2014).

Researchers have started to adopt a more pluralistic approach; that is, the use of multiple methodologies to better examine the different dimensions of a given domain (Chamberlain, Cain, Sheridan, & Dupius, 2011). Mixed method designs are becoming increasingly popular because they facilitate simultaneous analysis of a range of questions at multiple levels (Teddlie & Tashakkori, 2009). A mixed method approach provides a holistic theoretical perspective which encompasses both variable and person focused approaches. Constructivist grounded theory adopts the inductive and open-ended approach of grounded theory but acknowledges that social reality is constructed through relativism; the mutual creation of knowledge by the researcher and the participant

(Charmaz, 2000). According to constructivist grounded theory, the researcher is not a neutral observer; we must take their perspective into account as an inherent part of the research process (Charmaz, 2014). Constructivist grounded theory is therefore well suited to testing theoretical frameworks such as the ecological resilience framework (Windle & Bennett, 2011).

Most of what we know about resilience comes from quantitative research. Historically, qualitative researchers used quantitative criteria to interpret, explain and support their findings without acknowledging the differences between the two disciplines (Leininger, 1994; Meyrick, 2006). This assumes that variable focused quantitative approaches are gold standard. It is now recognised that the rigour of qualitative research cannot be judged by a quantitative 'yard stick'; we need a broader methodological framework that is sensitive to a range of epistemological standpoints (Denzin, 2009; Houghton, Casey, Shaw, & Murphy, 2012). The following sections outline the methodological approach used in this thesis.

2.10.2 Approaches to rigour

Lincoln and Guba (1985) argued that rigour is important when evaluating qualitative research, and proposed a number of criteria to determine rigour: credibility; transferability; dependability; and confirmability. The following paragraphs describe the strategies used to ensure Lincoln and Guba's criteria throughout the thesis.

Credibility is defined as the value, believability and confidence in the truth of the findings (Houghton et al., 2012). In this thesis, credibility was

ensured by examining the consistency of findings across mixed methods; both qualitative (Chapters 3 and 6) and quantitative (Chapters 4 and 5), at two points in time (Chapter 7). We employed multiple researchers at the data collection and analysis stages. We built trust and rapport with all participants, particularly those involved in the longitudinal research of Chapter 7. The findings of all empirical Chapters were presented back to participants before publication, and all participants were satisfied that the findings reflected their caregiving experiences. Finally, we emphasised unexpected findings throughout the thesis; for example, non-significant predictors in Chapter 4 and factors that do not map on to the resilience framework in Chapter 3.

Transferability is the extent to which qualitative findings can be applied to other contexts, while preserving the meanings from the original study (Leininger, 1994). In order to facilitate transferability, we included as much contextual detail as possible when presenting our findings, including demographic and care context information. Our methodological approach and findings have since been applied in other research areas, including resilience and poverty (Bennett, Reyes-Rodriguez, Altamar, & Soulsby, 2016) and resilience and visual impairment (Thetford, Hodge, Bennett, Knox, & Robinson, 2015).

Dependability and confirmability are closely linked (Houghton et al., 2012). Dependability refers to the stability of data and how consistent and repeatable it is (Graneheim & Lundman, 2004). Confirmability refers to the neutrality and accuracy of the data and the extent to which findings are shaped by the respondents, rather than researcher bias (Tobin & Begley, 2004). In

order to determine dependability, we sent all empirical Chapters for independent peer review in relevant journals. This ensured that the findings, interpretations and conclusions were supported by the data. In order to determine confirmability, we kept a reflexive diary during and after our interviews to document our methodological decisions, preconceptions, and initial impressions of the data. We employed multiple researchers at the data collection and analysis stages to ensure complementary as well as divergent understanding of the data. We regularly recoded existing data as new themes emerged in order to capture important findings that we might have missed. Both variable and person focused approaches have advantages and disadvantages, leading some researchers to include both (Masten, 2001). Multiple methods of complementary data analysis could better capture the multifaceted and complex nature of caregiver resilience.

2.10.3 Methodological approach of the thesis

This thesis uses a mixed method approach. There are a number of mixed method approaches, but one of the most common is an exploratory sequential design. This is when qualitative interview data identifies concepts that can then be quantitatively or qualitatively tested (Happ, 2009). In this thesis the exploratory qualitative work in Chapter 3 identifies the assets and resources using the resilience framework (Windle & Bennett, 2011), which informs the selection of variables to be tested in the exploratory quantitative work in Chapter 4. The emergent mechanisms of resilience from Chapter 3 are then quantitatively (Chapter 5) and qualitatively investigated (Chapters 6 and 7). The thesis is theory-led and methods are adapted to fit our research questions

(Chamberlain, 2012). Detailed quantitative methods information is provided in Chapters 4 and 5.

The qualitative work in this thesis uses a pluralistic hybrid approach which draws on the relativism of constructivist grounded theory (Charmaz, 2000) and the holistic, multi-level principles of mixed methods (Teddlie & Tashakkori, 2009). We used a purposive sampling technique to recruit spousal dementia carers from two dementia support groups and a care home in North West England. We approached the organisations by phone, before being invited to give a brief talk about the research. We interviewed all those who identified as being a carer and wanted to participate. Carer self-definition is a standard method of identifying carers (Hirst, 2004; ONS, 2011[b]), but leads to some variation in participant characteristics. For example, we interviewed both current and former spousal carers on the basis that both carry valuable caregiving experience.

We used constructivist grounded theory as an exploratory method to read and code the interviews (Bennett & Vidal-Hall, 2000). First, we read through each interview in its entirety to gain a contextualised understanding of the participant's experience. Each interview was coded line-by-line to identify open-ended codes which were then collapsed into focused categories (see Appendix 12). Finally, conceptual themes were formed based on focused categories across all interviews (see Appendix 13). The approach was reflexive so that emergent themes led to re-coding. We did not code for resilience at this stage. All interviews were coded blind by a second researcher; discrepancies were discussed until a consensus was reached. Consensus was reached in most

cases, but if themes differed then each coder re-examined and compared their previous open and focused codes until an agreement was made on the final themes. We theoretically sampled until we reached theme saturation (Charmaz, 2014). This occurred at 23 interviews, which exceeds Guest et al.'s (2006) theme saturation threshold of 12 interviews.

The next step was to identify resilient and non-resilient carers (Masten, 2001). Previous research defined resilience (Windle, 2011) and classified individuals as resilient or not according to independent criteria (Bennett, 2010; Moore & Stratton, 2003). We merged these to form a fully operationalised definition of resilience, consisting of the following five criteria:

i. Significant challenge, i.e. caregiving.

ii. No sign of (di)stress.

iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back).

iv. Actively participating in life (a sign of managing).

v. Current life seen as positive (a sign of adaptation).

Participants needed to fulfil all of the criteria to be classified as resilient. Each interview was classified blind by two researchers; discrepancies were discussed until a consensus was reached. Consensus was reached in most cases, but if classifications differed then each researcher re-classified their participants and compared criteria until an agreement was made. Classification addresses whether resilience can be achieved and characterises emergent facilitating and hindering resilience resources. Finally, we re-examined the initial codes to identify the factors that facilitate or hinder resilience. In line with the relativist

principles of constructivist grounded theory (Charmaz, 2000), we examined the extent to which these factors mapped onto the ecological resilience framework (Windle & Bennett, 2011). By classifying participants using independent criteria before this final stage, we avoid circularity in the findings. Although we had the framework in mind throughout analysis, it was theoretical in nature so we held few a-priori assumptions about the data.

2.11 Rationale and research questions

So far we know that dementia caregiving is uniquely burdensome, and the factors associated with this burden are well understood. We know that older spousal dementia carers may be particularly at risk of caregiver burden. However, carers are not a homogeneous group. We know less about carers who are not burdened by caregiving, and the factors associated with resilience. Resilience is inconsistently defined and measured. Studies identify resilience factors, but many of the findings are inconclusive and burden-centric. Relatively little of this research focuses on spousal dementia carers, despite the aforementioned. There is a growing consensus that resilience is best understood as an outcome, but the mechanisms leading to that outcome are not fully understood. Most of what we know about resilience comes from quantitative research methods. There is some longitudinal work but there is a lack of qualitative longitudinal research. There is a growing trend towards ecological models of resilience, but most studies examine resilience at distinct levels; few studies examine the dynamic interplay between individual, community and societal levels of resilience. To our knowledge, Windle and

Bennett's (2011) resilience framework has not yet been empirically tested in carers.

This thesis aims to use Windle and Bennett's (2011) ecological framework to identify and explore resilience in informal carers. This thesis extends the existing literature in terms of theoretical development, research methodology and sample. We specifically address the following research questions:

1. Can older informal carers achieve resilience?
2. What are the individual assets, community and societal resources that facilitate or hinder resilience in older informal carers?
3. What are the mechanisms through which individual assets, community and societal resources facilitate or hinder resilience in informal carers over time?

To address questions 1 and 2, part two uses qualitative (Chapters 3) and quantitative methods (Chapter 4) to explore the ecological resilience framework in older informal carers. Chapter 3 classifies older spousal dementia carers as resilient or not, identifies the factors associated with resilience, and examines whether they can be mapped on to the resilience framework. Chapter 4 considers the predictive relationships between individual assets, community and societal resources and resilience in a non-spousal, general, carer sample. To address question 3, part three takes key themes to emerge from part two and investigates the mechanisms through which they facilitate resilience. Chapter 5 uses quantitative methods to explore the age-related positivity effect in carers and non-carers across the life course. Chapters 6 and 7 extend and further

explore data utilised in Chapter 3. Chapter 6 explores the availability, function and perceived functional aspects of support and resilience in older spousal dementia carers. Using qualitative longitudinal follow-up data, Chapter 7 examines changes in resilience, assets and resources through care status transitions in older spousal dementia carers over time. Chapter 7 is the only Chapter to address research questions 1, 2 and 3.

PART TWO

EXPLORING THE RESILIENCE FRAMEWORK IN OLDER INFORMAL CARERS

Chapter 3

What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study[2]

3.1 Foreword

Some spouses find caregiving entirely burdensome whilst others find it life-enhancing; these carers are resilient. There is a growing trend towards ecological models of resilience, but most studies examine resilience at distinct levels; few studies examine the dynamic interplay between individual, community and societal levels of resilience. The current study uses a qualitative approach to examine spousal dementia carers' capacity to be resilient. We highlight the facilitating and hindering factors that participants draw on to achieve resilience, and whether they map on to the resilience framework (Windle & Bennett, 2011).

3.2 Introduction

Caring for a person with dementia is uniquely stressful (Lévesque et al., 1999). This burden often falls on family carers. 26% of primary carers in the UK are spouses (Alzheimer's Society, 2012). Pinquart and Sörensen (2003[a]), in an extensive review, noted that most studies centred on burden. However, burden is not the full story. Whilst stress, at least initially, is common to adversity, carers are not homogeneous (Bonanno, 2004). Some spouses might find caring entirely burdensome whilst others might find it life-enhancing; these carers are resilient (Windle & Bennett, 2011).

[2] This Chapter was accepted for publication in Aging & Mental Health on 13/10/2014 (Manuscript ID: CAMH-2014-0216.R1).

Resilience is often examined from a psychological perspective, emphasising psychological and trait resilience (Windle et al., 2010). Recently, work has emphasised the link between psychological resilience and community and social resilience (Wiles et al., 2012,). This is important since individuals may fail to become resilient if the community does not facilitate opportunities to adapt (Ungar, 2011). Despite this resilience is often narrowly defined and not well operationalised (Gaugler et al., 2007; O'Rourke et al., 2010). In light of these limitations, Windle (2011) defined resilience thus: "The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or 'bouncing back' in the face of adversity" (Windle, 2011; p. 163). Bennett (2010) operationalised resilience using the following criteria: participants view their current life positively; actively participate in life; return to or maintain a life that has meaning or satisfaction; be coping and not be distressed. There is still a need for an integrated, fully operationalised definition, which may be used to determine resilience in carers. Here, we draw upon both accounts to develop the following criteria for resilience: There must be a significant challenge, in this case caregiving; there must be no obvious sign of (di)stress; maintenance of a life of meaning and satisfaction (a sign of bouncing back); active participation in life (a sign of managing); and current life must be seen as positive (a sign of adaptation). Our conceptualisation addresses whether resilience can be achieved in our participants, and allows identification and characterisation of facilitating/hindering factors.

The literature supports these criteria. Carers with higher perceived control, who favour challenge over stability present with fewer depressive symptoms at follow-up (O'Rourke et al., 2010). Gaugler et al. (2007) found that high levels of resilience in dementia carers were associated with significantly less instances of institutionalisation at three-year follow-up. They characterised these resilient carers as more accepting of support. However, the type of support is important; support may be detrimental if it creates feelings of over-dependence (Ingersoll-Dayton, Morgan, & Antonucci, 1997) or if it is not empathic (Haley, Levine, Brown, & Bartolucci, 1987). Carers may prefer and compare themselves with those in a similar situation (Farran, Loukissa, Perraud, & Paun, 2004). Formal support and service provision are important. Support services designed to provide practical support to encourage carers to remain socially active and maintain healthy living are highly valued by those carers with access to them (Seddon et al., 2009). Resilience, therefore, can be fostered within the individual, their immediate surroundings and wider social environment.

Windle and Bennett's (2011) theoretical model of resilience for carers (see Figure 3.1) posits that each carer draws on individual assets. They emphasise that carers do not exist in isolation but interact with their environment by drawing on community and societal resources. Carers use these assets and resources to facilitate or hinder resilience. The absence of assets and resources may lead to compromised wellbeing or further caring challenges. To our knowledge, no qualitative work has been conducted examining factors associated with resilient carers, nor to examine whether qualitative themes can be mapped on to the framework.

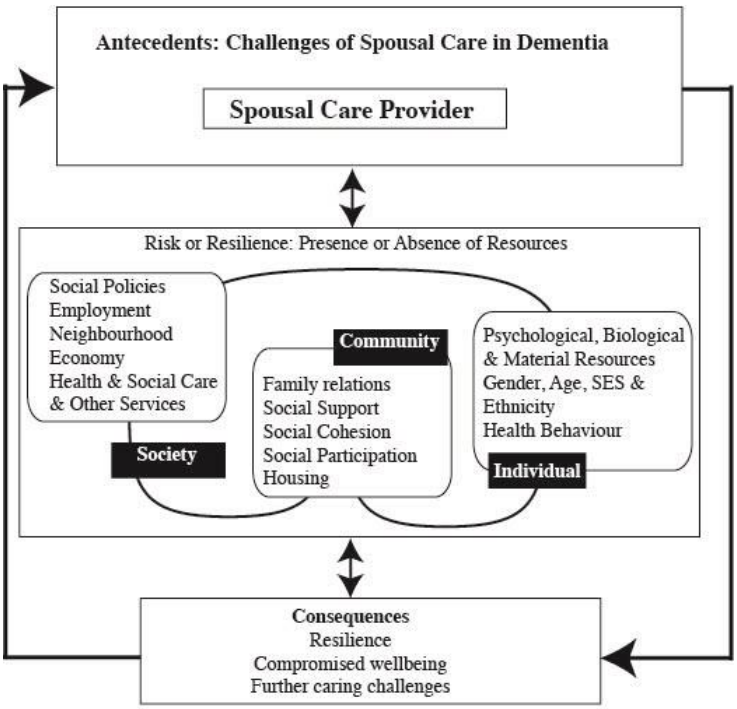

Figure 3.1: The Resilience Framework applied to spousal carers (Windle & Bennett, 2011).

We use a qualitative approach to examine spousal dementia carers' capacity to be resilient. Our participants are classified as either resilient or not using the criteria above. We highlight the facilitating and hindering factors that participants draw on to achieve resilience, and whether they map on to the resilience framework (Windle & Bennett, 2011). The primary research question asks: Can spousal dementia carers achieve resilience? The first objective addresses which assets and resources the carers draw on that facilitate or hinder resilience. The second addresses: How do these assets and resources map on to the framework?

3.3 Methods

3.3.1 Participants

We recruited from two dementia support groups and a care home in North West England. The first author made contact with each organisation by phone, before being invited to give a brief talk about the research. Although 35 carers volunteered, this paper focuses on the 20 participants who provide spousal care. This exceeds the minimum theme saturation threshold of 12 interviews; the point at which no new information or themes are observed in qualitative data (Guest et al., 2006). There were 13 women and seven men. Each had been caring for their spouse for between 2 and 10 years (mean = 5.62 ± 2.73) and had been married for between 28 and 61 years (mean = 50.35 ± 7.36). Age ranged from 62 to 86 (mean = 75.95 ± 7.47). Most participants lived with and cared for their spouse at home although two were already widowed (Mrs L., Mr Gr.) and another had admitted her husband into nursing home care (Mrs G.). Care recipients had different levels of impairment and care durations did not always correspond with the time of diagnosis. For example, Mrs F. had provided eight years of care to her husband, but he only had a formal diagnosis of dementia for three years. The socioeconomic status of the participants was broadly representative of similar demographics in the British population (ONS, 2011[a]).

3.3.2 The interview

Semi-structured interviews were conducted and recorded during monthly carer meetings. Private interviews, lasting between 25 – 90 minutes, were conducted by the first author and by two research assistants, Lauren Walsh and Naomi

Hayes. The interview began with factual questions (section A): age; marriage; care duration; and employment (see Appendix 8). We used an open chronological and retrospective approach to allow feelings and events to be traced to specific stages of care. Section B asked about life before the presentation of cognitive impairment. Participants described a typical day spent alone and with their spouse, relationship quality, division of responsibility and type and amount of support given and received. Participants were asked about the period surrounding diagnosis or first suspicions of impairment (C) and their initial emotional and behavioural reactions to the news. The final section (D) concerned the present, repeating section B's questions in light of current circumstances. Concluding questions prompted participants to consider which of their own personal characteristics may have helped them as a carer. They were given the opportunity to provide advice and recommendations for formal practice and legislation. The study received ethical approval from the University of Liverpool Research Governance Committee, and all identifying features have been anonymised (see Appendix 1).

Table 3.1: Demographic details and resilience classification of carers.

Carers (N=20)	Age (years)	Marriage duration (years)	Care duration (years)	Resilient/Not resilient
Mrs W.	62	28	3	Not resilient
Mrs C.	68	48	9	Resilient
Mrs Wi.	69	51	4	Not resilient
Mrs F.	71	51	3	Not resilient
Mrs L.*	73	53	10	Resilient
Mr G.	81	52	5	Resilient
Mrs G.**	82	49	5	Not resilient
Mrs Go.	69	40	5	Resilient
Mrs O.	77	59	2	Not resilient
Mrs S.	86	61	6	Not resilient
Mr Go.	74	52	10	Resilient
Mr Wh.	71	50	10	Resilient
Mr H.	81	53	5	Not resilient
Mrs P.	75	49	4	Not resilient
Mr N.	71	41	7	Resilient
Mr Gr.*	88	56	9	Not resilient
Mrs H.	89	58	7	Not resilient
Mrs La.	83	55	2.5	Not resilient
Mr Ha.	80	52	3	Resilient
Mrs Cl.	69	49	3	Not resilient

Key: *Widowed **Institutionalised.

3.3.3 Method of analysis

We used a three-stage hybrid method in our analysis (see Bennett, 2010). We used a grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995) as an exploratory method to read and code the interviews. We adopted this method without a-priori assumptions about the data. However, the remaining analysis then departed from the principles of classical grounded theory to identify resilience and identify which factors were associated with resilience in the ecological framework (Windle & Bennett, 2011).

1) The first author read through each interview in its entirety to gain a contextualised understanding of each participant's experience. Interviews were then coded line-by-line and focused codes were developed (see Appendix 12), before identifying themes based on all interviews (see Appendix 13). The approach was reflexive so that each emergent theme led to re-coding. All interviews were then coded blind by the second author. A consensus was reached between the two coders. Some prominent themes to emerge at this stage were: resilience; staying positive; knowledge and expertise on dementia; and shared experience.
2) Next, we re-read the interviews to identify participants as resilient or not. Each author classified each participant independently, using the same method as above. We used the criteria outlined earlier:
    i. There must be a significant challenge: caregiving.
    ii. No sign of (di)stress.
    iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back).
    iv. Actively participating in life (a sign of managing).
    v. Current life seen as positive (a sign of adaptation).
3) Finally, we re-examined the codes from stage one in order to identify the factors that facilitate or hinder the capacity for resilience as identified at stage two. We specifically addressed two research objectives: We identified which individual assets and community and societal resources participants drew on to facilitate or hinder resilience, and whether they mapped onto the resilience framework. By classifying our participants

first, using an independent set of criteria (Bennett, 2010), we avoided circularity in the findings.

3.4 Results

3.4.1 Classification

Our primary research question was: Can spousal carers achieve resilience? We identify eight participants as resilient. Thus, some spousal dementia carers can achieve resilience. The following will determine the multi-dimensional nature of resilience; e.g. some resilient participants draw on factors that hinder resilience and some non-resilient participants draw on factors that facilitate resilience. Resilient participants are younger (mean = 73 years ± 4.81) than non- resilient participants (mean = 78 years ± 8.58). Resilient participants have been caregiving for longer (mean = 7 years ± 2.77) than non-resilient participants (mean = 4 years ± 2.06). Men were more likely to be resilient (5/8), women less so (10/12) (see Table 3.1). The following illustrate resilient and non-resilient participants:

Mrs C. is classified as resilient because she shows no obvious signs of distress. She has adapted to becoming a dementia carer and views her current life positively as she adopts a positive outlook from the point of diagnosis and continues to instil this in her husband:

> It changed and yet I tried to be positive and say all they've done is give it a name. You're still the same person you were yesterday. (Mrs C.)

She ensures that both her and her husband maintain a life that has meaning and satisfaction by continuing to travel on holiday and engage with the local

community. She has bounced back from the initial challenge of becoming a carer:

> We've been very lucky. We travelled before he got Alzheimer's and we continued to travel with Alzheimer's up until two years ago when it got too difficult. We realised all the things we wanted to do in retirement so we didn't let it stop us. (Mrs C.)

Mrs C. actively participates in life, managing charity work and attending support groups:

> I've got to go out every day. He's at an allotment this morning ran by [charity]. That's a charity I've accessed an awful lot, they've been invaluable. (Mrs C.)

Conversely, Mrs W. is not resilient because she is distressed; she is not positive about her current life and seems resigned to her circumstances:

> This is my retirement in other words. Not what I planned of course but there you go. (Mrs W.)

Mrs W. has not managed to bounce back as she focuses mainly on those things that have become lost or changed irreparably, rather than maintaining existing competencies:

> It's not husband-wife anymore it's carer-caree… It's like looking after a child. (Mrs W.)

Although Mrs W. participates in a carer support group, she does not welcome social support from her family and so does not fully participate in life:

> I do have a problem with family support because we don't get many phone calls from his lot. We don't encourage them to come up to be

> honest because he doesn't like visitors, well it's not that he doesn't like people, he loves people. (Mrs W.)

3.4.2 Mapping resilience factors on to the resilience framework

Our research objectives addressed; (1) which resources carers draw on that facilitate or hinder resilience, and (2) how these might map on to the resilience framework. Although the process of analysis happened sequentially (see Section 3.3.3), we integrate them in our presentation.

3.4.3 Individual level of the resilience framework

3.4.3.1 Psychological assets

The first theme is maintaining continuity. Whereas all participants emphasise the decline in function of the care recipient, some participants maintain and encourage aspects of their spouse's former self. Mrs Wi. actively encourages aspects of her husband's former lifestyle:

> He used to go out every Monday and every Friday playing snooker and that hasn't stopped. He goes on his own because I've told them right from the beginning about [husband] having Alzheimer's. (Mrs Wi. Not resilient)

The maintenance of self-identity and existing competencies re-emphasises the fact that resilience may not just concern adjustment and change, but concerns the management of stress and maintenance of normal functioning. Carers do not flourish or become 'super functioning'; they maintain previous functioning by actively emphasising features of their previous life. Another theme is the ability to stay positive:

> I'm positive. I laugh and I sing and she laughs and I act soft in the house. I've even said to one of the neighbours about my singing and she says [Mr Go.] it's a good job we've got a detached house. I sing at the top of my voice. (Mr Go. Resilient)

Humour is important in facilitating resilience and is mutually enriching for carer and care recipient alike. Participants frequently use downward comparison when referring to others:

> I was getting a little bit depressed and then I have a talk to myself and I think there's millions of people like these and in one respect he's been lucky if he's going to have it that he got it when he was eighty and not fifty. (Mrs S. Not resilient)

This facilitates resilience by diverting attention from the challenge of caregiving and providing meaning so that, given the wider context, carers appreciate their own circumstances which become normalised. In contrast, some participants have a more negative outlook which hinders resilience. These participants tend to be non-resilient:

> If there is a problem that's weighing you down a bit you just work at it, don't you? That's your life. You've had the best and now you've got to put up with the worst. (Mr Gr. Not resilient)

Resilient participants do not simply stay positive in spite of burden; they use caregiving as an opportunity to acquire expertise on dementia. Whilst the ability to acquire knowledge is an individual asset, the carer interacts with the community and uses societal resources:

> I went on the internet, got up what medication he should be on… and I was like a dog with a bone basically. We just became proactive. Within a

> couple of weeks I went to the Alzheimer's [support centre] and I just sort of took on board everything but, it's 9 years later and you're still learning all the time. (Mrs C. Resilient)

Psychological assets seem to be dominant in our sample. But these interact with community and societal resources, as Mrs C. highlights. One might suggest that attempts made to promote resilience should start with individual psychological assets, as it is Mrs C's drive to acquire knowledge that leads her to interact with wider services.

3.4.3.2 Material resources

Most participants report having sufficient finances but having access to disposable income facilitates resilience by leading to a better quality of life for the carer and care recipient alike. We have already shown how Mrs C.'s financial capacity allowed her to continue travelling. For other participants, access to disposable income is not always useful and sometimes hinders resilience, as Mr Ha. explains:

> We're spending no money. We have a system at the bank where it clears it down to £2000 for the rest of the month and the rest it clears away. I could well afford to buy anything I just can't think what to buy. (Mr Ha. Resilient)

Specifically, access to material resources may not necessarily equip someone to be resilient. Although Mrs La. claims to have had a very good life, going on cruises and on 'wonderful dancing holidays' with her husband prior to his dementia, she now feels differently:

> I feel I'm a prisoner. It's a prison sentence for me and for him because you've lost the freedom we had before. (Mrs La. Not resilient)

3.4.4 Community level

3.4.4.1 Family relations

Although most participants value the support they receive from family members, many prefer family to be 'hands off' rather than over-involved, and to provide practical rather than emotional support. This theme is characteristic of even the most resilient of participants, as Mrs C. describes when referring to her two adult daughters:

> We said you've got your own children now all in school, your husbands with jobs. We will get help from other people. We will find help as and when we need it. (Mrs C. Resilient)

Other participants hold strong views on the role of family support. Although Mr Ha. acknowledges that his daughter has been present and sympathetic, he goes on to say:

> Our daughter has been coming over Sunday afternoon regularly lately. I don't really want her to, it's my place. (Mr Ha. Resilient)

Although resilient, Mr Ha. is generally dismissive of support whereas Mrs C. appreciates the importance of support. Carers may prefer it if they control the amount of family support they receive to maintain independence and avoid feelings of over-dependency.

3.4.4.2 Social support

Friends, and particularly friends in similar circumstances, are a great source of support. Social support facilitates resilience most when participants are able to demonstrate and share their expertise and insight with others. This is illustrated by two interviews with participants who are friends through a support group; Mrs C. advises Mrs Wi. with regards to a specific problem:

> Her husband got a strop on this morning because he kept asking her the time and she was saying 5 to 10 5 to 10 and she said it's because you're deaf. She said he got so angry and stormed upstairs and I said oh, cause we don't mind telling each other stuff, two things there, I said one; you're pointing out another failing which makes him feel bad, and the other thing is; you need to look at does he know what 5 to 10 means. (Mrs C. Resilient)

> When I got in [Mrs C.] said well he might not be recognising what 5 to 10 is… you see you learn something every day and you think you're down but knowing that somebody else has got another look on it. (Mrs Wi. Not resilient)

This specialised and confident application of knowledge highlights dementia carers as experts on the condition as well as their care duties. The receipt of advice can be as important as the provision of advice. Resilience might predispose individuals to take control of the role, garner information and become experts; this knowledge can then be passed on to others in the same situation. Sharing advice demonstrates carers are embedded in a wider social arena.

This type of stable and supportive friendship is less common in the non-resilient:

> People drop out, you know, friends. They don't fall out with you but you can tell they're not in. There's nothing for them anymore. You've got no conversation and they've got their own lives and their own friends and that's a bit hard. So you are a bit isolated. (Mrs H. Not resilient)

This category represents an interaction between each level of the resilience framework. Mrs C. and Mrs Wi. met in the support group, a societal resource, before sharing individual resources on a community-level.

3.4.4.3 Social participation and cohesion

Many participants emphasise the social groups they are part of, and the function they serve. Participating in social groups facilitates resilience:

> I'm in an international Christian group which is good because not only do you have spiritual direction but you have the group supporting you. And whatever you say is confidential. (Mrs La. Not resilient)

Some of the more well-supported participants emphasise the value and function of the dementia support groups, in particular. The friends made here are a more highly regarded source of social support by all who have them, as Mrs Go. explains:

> Coming here has helped me because the people that come here are in the same position as I am. They've been in it longer than me some of them so

> I can use their experience and I can relate to what they're saying. (Mrs Go. Resilient)

For some non-resilient participants, attending groups is the only form of social support they have access to:

> I don't think there is anybody apart from going the coffee mornings… my daughter is distressed so I couldn't really put it on her. (Mrs Cl. Not resilient)

Dementia support groups facilitate resilience by providing a forum to acquire and share information by using the expertise of other carers. Support group friendships provide a source of practical and emotional reassurance.

3.4.5 Societal level

3.4.5.1 Health and social care

Participants make use of many different health and social care services, including day and respite care, home help and support groups. Resilient participants are more likely to acknowledge their own limitations and know when to take a break. Eight out of 20 participants in our sample refer to some form of respite care and 4 participants use it. Those who use respite are more likely to be resilient than those who do not, so it represents an important facilitator of resilience:

> I'm getting respite on a weekend. I really do know the meaning of recharging my batteries now. I feel more, you know, on the Monday morning right let's get on with the day. (Mrs C. Resilient)

Some participants like the idea of respite care but do not know that it is available to them:

> If carers could get respite care on a regular basis that'd be a most wonderful thing because it would give them the strength to go on, wouldn't it? Rejuvenate them. (Mrs La. Not resilient)

Reducing or temporarily removing the objective burden caused by the care recipient provides an opportunity to 'recharge' some of the individual assets of resilience. Although respite care facilitates resilience for both carer and care recipient, not all participants draw upon it. Our non-resilient participants are least likely to use this service; either they are unaware of the service; do not know how to acquire it; or feel that they are not ready for it.

3.4.5.2 Other services

Some participants take part in unique innovative services which facilitate resilience:

> We helped make a DVD for [local health service]. They interviewed the two of us together… His theme song for that is always look on the bright side of life [laughs]; the Monty Python one. (Mrs C. Resilient)

Mrs Wi. spoke of a pilot scheme that she is part of at the local memory clinic:

> I do voluntary work as well… I'm a carer talking to the carers… they ask the questions and I say and that's where I learnt about that… I know it sounds daft but it is a break away, it's different, and yet you're helping others. (Mrs Wi. Not resilient)

These services are different from the latter health and social care services, in that the participants seem more engaged with them. Carers may be more likely to use societal resources if they can provide social support to others in the same

situation. Services which encourage independence and 'giving back' rather than dependence may be preferred. This represents an interaction between societal resources and community resources.

3.5 Discussion

We asked whether spousal dementia carers could achieve resilience. We demonstrate that some can achieve resilience, although the picture is more complex. Our research objectives were to identify the assets and resources carers draw on that facilitate or hinder resilience, and to address how these might map on to the resilience framework (Windle & Bennett, 2011). We identified several factors that facilitate or hinder resilience in spousal dementia carers and found that these map well on to the levels of the framework.

Facilitating factors emerged primarily at an individual level, and included psychological assets which were frequently associated with resilient participants. Maintaining continuity showed that resilience is about bouncing back to previous functioning rather than flourishing beyond previous functioning (Smith et al., 2008; Windle & Bennett, 2011); it could be those carers who need to adapt least who are most resilient. Staying positive has several beneficial functions: positive cognitions buffer against sources of burden (Zausznieski et al., 2009); enjoyment in the role reduces burden and depression (Pinquart & Sörensen, 2003[a]); and sharing a joke can maintain companionship (Murray et al., 1999), reciprocity (Voelkl, 1998) and the care recipient's sense of identity (Hellström, Nolan, & Lundh, 2005)[3]. Downward

[3] Indeed, Kalisch et al. (2015) argue that staying positive in the face of adversity is fundamental to resilience.

comparison with those that are 'worse off' may be an important way of increasing self-efficacy and the carer's confidence in how well they are doing (Farran et al., 2004). The acquisition of knowledge supports existing dimensions of resilience, such as favouring challenge and garnering control (O'Rourke et al., 2010). Facilitating factors emerged at a community level, including friendships with common experience and social participation. Friends provided mutual experience and shared understanding for dementia carers, and good quality social relationships were reinforced through shared experience (Farran et al., 2004)[4].

Hindering factors emerged at individual and community levels of the ecological framework. Individual factors such as negative outlook, and focusing on aspects that have become lost or irreparably changed, are frequently associated with non-resilient participants. At a community level, perceived or actual loss of friends hindered resilience, and increased feelings such as isolation. This supports Gaugler et al. (2007), who characterised highly resilient dementia carers as more accepting of informal support. Some factors are only facilitating up until a point, after which they may become hindering. Our data gives examples of this from individual, community and societal levels; at an individual level, a sense of freedom and access to disposable income may be limited by the demands of dementia. This finding is unexpected and would not be predicted by the resilience framework, which might have predicted that a lack of material resources was instead a hindering factor. The fact that our participants did not raise lack of money as a negative issue is not to say that it is

[4] Dementia carers regard learning from other carers as particularly valuable; for example, strategies to manage challenging behaviours (Murphy, Casey, Cooney, & D'Eath, 2014).

not a valid factor. No empirical research has looked directly at the role of material resources in facilitating resilience. At a community level, family support that is perceived as over-intensive may create feelings of dependence. This is unexpected given that carers often prefer social relationships based on shared experience, and family members are likely to share more experience than friends (Farran et al., 2004). Pinquart and Sörensen (2000) suggest that this may be because family are structurally determined and associated with negative social exchange surrounding the sick relative, whereas friends are selected and associated with the 'good old times'. At a societal level, respite care is valuable but some participants feel that they are not ready for it or are unaware of its availability. Thus, access to resources is not always sufficient; carers must wish to use them. This supports Bennett's (2010) view that the time has to be right to achieve resilience.

The current study contributes much that is new. First, by focusing on spousal care, we provide a novel perspective through which we examine resilience. Qualitative interviews examine the individual experience of dementia care; however, we were also able to identify a number of community and societal resources. Unexpectedly, few societal resources emerged from our analysis[5]. The resilience framework suggests that social policy, employment, neighbourhood and economy issues might emerge but they did not. This may be due to the nature of our interview; we asked questions that focused on psychological and interpersonal aspects of the caregiving experience, encouraging participants to talk about their affective and behavioural reactions.

[5] This is in line with Joling et al. (2015[a]), who found that dementia carers highlight the role of personality and coping strategies over and above external resources such as social and professional support.

Wild, Wiles and Allen (2011) found that social resources emerged predominantly when participants were asked about community, household and neighbourhood issues. Despite this, we uncovered some important societal factors which seem to facilitate resilience in our participants. By operationalising resilience, we were able to identify who is resilient and who is not, which may aid the promotion of resilience through formal and informal intervention. A limitation of this study is that the majority of the sample is recruited from dementia support groups, which may represent a resilient sub-group of participants such that the findings cannot be generalised to other non-resilient carers. However, 6 out of 20 participants were recruited from outside support groups and not all those participants recruited from support groups are resilient. Furthermore, it is difficult to recruit those carers who are not known to services and so emphasis should be placed on extending our findings to them. Another limitation is that the notion of drawing on assets and resources, and the classification system used, may be too simplistic. We showed that some factors are only facilitating up until a point, after which they may hinder. We found that some resilient participants draw on factors that hinder resilience and some non-resilient participants draw on factors that facilitate resilience, suggesting that resilience is multi-dimensional. Further discussion of these issues goes beyond the scope of this paper. Our study emphasises the need to integrate resilience within an ecological framework (Windle & Bennett, 2011), using different methods of research and analysis.

In conclusion, a resilient carer is someone who stays positive in the face of care demands and actively maintains and preserves their relationship and loved one's former self. Resilient carers have access to and use services such as

respite care and may actively engage with innovative schemes that aim to 'give back' to others in similar situations. Resilient carers are knowledgeable and well supported by family but especially friends, with whom they share this knowledge. Support group friends share emotional and practical advice and reassurance that may help the carer manage their role better. In doing so, carers may be more encouraged to pursue the positive aspects of caring which buffer the effect of burden on resilience. Resilient carers can be encouraged to share their knowledge and expertise with those who are not resilient. The ideal forum for this is the support group setting; a societal resource, within which individual assets and community level resources can be facilitated. Formal services could step in to help potentially at risk individuals, such as those who are not resilient and/or those without knowledgeable peers. Our findings emerge on individual, community and societal levels, which suggest that resilience is a multi-dimensional construct and supports the continued need to examine resilience from an ecological perspective.

Chapter 4

Using an ecological framework to predict resilience in older informal carers: The role of individual assets, community and societal resources[6]

4.1 Foreword

Chapter 3 used qualitative methods to identify a number of individual assets, community and societal resources that facilitate or hinder resilience in older spousal dementia carers. These findings have not been tested quantitatively, and we do not know whether they apply to a non-spousal informal carer sample. Informed by Chapter 3 findings, the current study takes a cross-sectional subsample of current carers from CFAS Wales data to examine the individual assets, community and societal resources that predict resilience in older informal carers.

4.2 Introduction

Since 2001, the number of informal carers living in the UK has risen from 5.8 million to 6.5 million (an 11% increase; ONS, 2011[a]). Around half of these carers are aged over 50, and 1.3 million are aged 65 or older (ONS, 2011[a]). There are physical, emotional, social and financial stressors associated with the provision of informal care (Etters et al., 2008). This causes a range of physical and mental health consequences (Pinquart & Sörensen, 2003[a]; Pinquart & Sörensen, 2007; Sörensen et al., 2002). However, carers are not a homogeneous

[6] Submitted as a manuscript to Research on Aging on 13/1/2017 (Manuscript ID: ROA-17-012). Awaiting reviewer feedback.

group; some may be vulnerable to these stressors, whereas others may not. This latter group may be resilient. Resilience has been defined as:

> "The process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity" (Windle, 2011; p. 163).

Traditionally resilience has been examined on an individual level, emphasising psychological and trait aspects (Bonanno et al., 2007; Kalisch et al., 2015; Windle et al., 2010). Indeed, carers define resilience in terms of individual factors (Joling et al., 2015[a]). Psychological resilience has been associated with various individual characteristics (Gaugler et al., 2007), including: optimism; self-efficacy; self-esteem; acceptance; emotional intelligence; mastery; and stress resistance (Carbonneau et al., 2010; Cherry et al., 2013; Deist & Greeff, 2015; Windle et al., 2008). However, interpersonal and socio-environmental factors are also important (Bennett & Windle, 2015; Liebenberg & Ungar, 2009); without these, the majority of people cannot become resilient (Bennett & Windle, 2015; Ungar, 2011; Ungar & Lerner, 2008). There is evidence to suggest that psychological resilience is distinct from but associated with the outcome of resilience in carers. In a study of bereaved spouses, Spahni et al. (2015) found that psychological resilience and pre-existing relationship quality predicted resilience. We are unaware of any research that has examined this relationship in relation to informal carers. For the purposes of this study, we use the term 'resilience' to refer to resilient/non-resilient outcomes; the extent to which the individual has negotiated with, managed and adapted to caregiving challenge.

We use the term 'psychological resilience' to refer to the intra-individual characteristics that predict resilience.

Windle and Bennett (2011) developed an ecological model of resilience applied to carers, which posits that each carer draws on individual assets, community and societal resources which interact to facilitate or hinder a resilient outcome (Figure 4.1). The following subsections summarise the existing literature under each level of the framework.

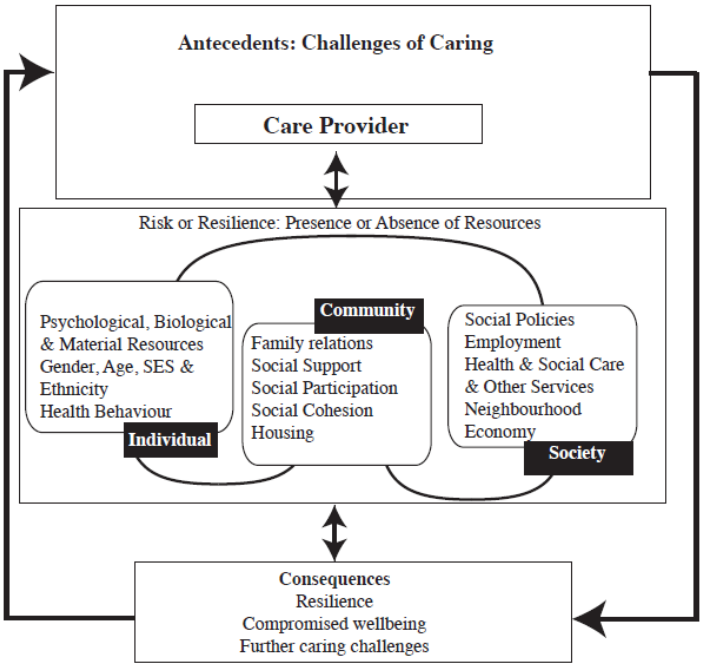

Figure 4.1: The Resilience Framework applied to informal carers (Windle & Bennett, 2011).

4.2.1 Individual assets

Demographic factors are associated with resilience in carers, but the relative association between demographic factors is mixed across studies. Some studies show that women make more resilient carers (Gaugler et al., 2007; Netuveli et

al., 2008), whereas others find men more so (Fuller-Iglesias et al., 2008; Donnellan et al., 2015). It is unclear in the gerontology literature whether there are gender differences in depressive symptomology, life satisfaction, or loneliness, although it is clear that women of all ages are more burdened by caregiving than men (Gibbons et al., 2014; Jessup et al., 2014; Pöysti et al., 2012; Takano & Arai, 2005). Calasanti and King (2007) explain that caregiving is more difficult for women due to role expectation and less delegation of care duties. However, Russell (2007) argues that, rather than experiencing less burden, men may express and handle their burden differently than women, taking a managerial approach to caregiving (Cherry et al., 2013; Gilbert et al., 2014).

Resilience research has failed to establish conclusive carer age differences. Windle et al. (2010) found that psychological resilience moderates the relationship between ill-health and subjective wellbeing in older adults aged 60 and over, but the effect weakens with age. In our qualitative work we found that non-resilient spousal carers were older, with a relatively greater proportion in their advanced 80s (Donnellan et al., 2015). Despite older carers being less resilient, having poorer health status and being reliant on more health and welfare services (Pinquart & Sörensen, 2007; Rosness et al., 2011), they have better quality of life, and find caregiving more rewarding and less burdensome than younger carers (Raschick & Ingersoll-Dayton, 2004). Research on younger informal carers of people with Early Onset Dementia shows they experience relatively more burden, stress and depression (Grønning et al., 2013; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010), even when dementia severity and behavioural disturbance are controlled (Freyne, Kidd,

Coen, & Lawlor, 1999). This may be because caregiving is more common for older, compared to younger people, who have more competing demands such as workload and childrearing commitments (Ablett & Jones, 2007; Scharlach, 1994). More research is needed to assess the extent to which demographic variables, such as age and gender, are associated with resilience in informal carers.

There is a lack of research on material resources and resilience in carers (Donnellan et al., 2015). Studies show that low socioeconomic status in informal carers is associated with poorer physical health (Pinquart & Sörensen, 2007) and higher levels of anxiety and depression (Zhou et al., 2014). Research has failed to establish a reliable association between socioeconomic status and resilience in older adults (Netuveli et al., 2008). Pöysti et al. (2012) found that lower education status in male carers is associated with less burden. Gaugler et al. (2007) found that higher income and education are associated with lower resilience in dementia carers, but there is no effect of being employed on resilience. Material resources may be limited by the demands of caregiving; some spousal carers are unable to spend the money they have saved, or enjoy the retirement they have planned on, which hinders resilience (Donnellan et al., 2015). It is possible that SES is too broad a metric, therefore, research should isolate specific aspects of SES (e.g. employment) before examining in relation to resilience.

4.2.2 Community resources

Carers interact with others and utilise informal and formal support systems (Wiles et al., 2012). Research shows that larger social networks facilitate resilience and subjective wellbeing (Gaugler et al., 2007; Ross et al., 2003; Walsh, 2012). However, it is unclear whether the quantity or quality of support best captures the resilience and heterogeneity of carers (Luthar, 2006; Roth et al., 2005). For example, Han et al. (2014) found that affectionate support and positive social interaction specifically reduce psychological burden and the prevalence of major depressive disorder in dementia carers (Han et al., 2014). Pinquart and Sörensen (2000) found that subjective wellbeing is predicted by emotionally-close contact with relatives, and the frequency of contact with friends. This suggests that resilience may not be solely determined by the structural composition of social support. Positive perceptions of support, such as perceived satisfaction with support, may have an indirect effect on subjective wellbeing and resilience (Deist & Greeff, 2015; Ellwardt et al., 2013; O'Rourke & Tuokko, 2000; Roth et al., 2005; Sherman et al., 2013). Previously, we found that spousal dementia carers can perceive family support as over-intensive, and may wish for it to be 'hands-off' to maintain independence. Carers may also perceive friendships with those in similar circumstances as more supportive than those without common ground as they can share knowledge and expertise (Donnellan et al., 2015). Rather than employing standard composite measures of support, research should measure carer perceptions of different types of support (e.g. emotional, practical) from different social networks (e.g. family, friends). This may better capture some of the complex interpersonal aspects of resilience mentioned above.

4.2.3 Societal resources

A significant amount of evidence shows that those who participate in social activities are more likely to be resilient (Bennett, 2015[b]). Health and welfare provision enhances resilience, especially in dementia or residential care; for example, the use of domiciliary nursing care for care recipients has been shown to reduce depressive symptoms in carers (Rosness et al., 2011). The use of institutional respite care, day-care, home-help services and overnight stays at hospital predict reduced carer stress and burden (Pickard, 2004), high resilience (Gaugler et al., 2007) and delayed institutionalisation (Pickard, 2004). Carer support groups can provide emotional and informational dimensions of support and resilience and reduce psychological distress, depressive mood, and burden (Han et al., 2014). Research shows that spousal carers may benefit most from services that reduce the objective level of stressors, such as day-care services or institutional respite care (Pickard, 2004).

Unfortunately, societal resources may be relatively less available than individual assets and community resources. Carers may hold few expectations of assessment and present modest service requests (Windle & Bennett, 2011). Health and social care provision in England is biased towards practical aspects of caring, with 37% of service outcome assessments granting support with domestic activities, and less attention paid to psychosocial and interpersonal aspects, with only 3% granted emotional support (Windle & Bennett, 2011). One review showed that, between 1993 and 2006, over half of carers' requests for flexible in-home respite care and counselling support were not being granted by a Welsh carer assessment (Pickard, 2004; Seddon et al., 2006).

Support services designed to provide practical support to encourage carers to remain socially active and maintain healthy living are valued by those carers with access to them (Seddon et al., 2009). These societal resources represent an important forum within which individual assets and community resources can be shared (Donnellan et al., 2015). Societal, much like community resources, facilitate resilience only if they are tailored to the individual's needs. Relatively little research examines whether formal social groups facilitate resilience in informal carers. Carers use a range of health and welfare services, and yet the literature isolates and emphasises individual services (e.g. respite) in relation to resilience. A composite measure is likely to represent carer service use more accurately.

4.2.4 Research question

Although it is essential to consider the full ecology of resilience in caregiving, little research examines the integrated effect that all levels have on resilience. Windle and Bennett's (2011) ecological resilience framework has only been qualitatively explored with spousal dementia carers (Donnellan et al., 2015). We are unaware of any existing quantitative research that has tested the framework with informal carers. The current study takes a cross-sectional subsample of current carers from the Cognitive Function and Ageing Study Wales (CFAS Wales). Informed by existing literature and the resilience framework, we examine measures of age, gender, social class, psychological resilience, frequency of family and friend support, emotional and practical support from family and friends, social groups, and health service use. We aim to specifically address one key research question: Which individual assets,

community and societal resources significantly predict resilience in a sample of older carers?

4.3 Methods

4.3.1 Data

Cross-sectional data was originally drawn from Wave 1 of CFAS Wales; a longitudinal population-based study looking at health and cognitive function in community-dwelling older adults living in two research centres in urban and rural Wales. 3593 respondents were randomly sampled from general practice lists between 2011 and 2013, with equal numbers drawn from 65-74 and ≥75 age groups. Data was collected from face-to-face interviews conducted in the respondent's home by trained interviewers. Ethical approval was granted by the appropriate NHS Ethics committee (ethics information available on request).

This paper focuses on a subsample of current carers (N=646) aged 65 and over. Carer information in CFAS Wales is limited, so we used the following question: "Is there anyone who is frail or unwell and needs your help with day to day tasks?" Self-report is the standard survey method of classifying carers, used by British Household Panel survey (Hirst, 2004) and the 2011 UK Census (ONS, 2011[b]). 76% of the sample was providing care due to physical frailty, 10% due to mental frailty, and 14% due to both. None were institutionalised. The vast majority were retired (91%) and living in a house or flat (97%). Most were married (75%), with 14% widowed and 11% either single, divorced/separated or cohabiting. No further information specific to the

caregiving context was available from the data set. However, the majority of the sample provide care to the physically frail, and are mostly old (74 ± 6.60) and married, so we could infer that the average respondent is caring for a spouse with physical frailty. Further respondent characteristics can be found in Table 4.1.

4.3.2 Measures

4.3.2.1 Outcome variable

A standard method of operationalising resilience is: high/low functioning against a measure of high/low adversity or risk (Masten, 2001). Studies have classified resilient individuals from high life satisfaction (Chappell & Dujela, 2008; Diener, Emmons, Larsen, & Griffin, 1985), high quality of life in the presence of health-related or psychosocial adversity (Hildon et al., 2010), and low levels of distress in the face of caring for a relative with severe dementia (Joling et al., 2015[b]). Unfortunately, CFAS Wales does not include specific measures of resilience or adversity. We do, however, have a measure of life satisfaction and depression; resilient individuals have been characterised as having high life satisfaction (Chappell & Dujela, 2008) and few or no depressive symptoms (Galatzer-Levy & Bonanno, 2012; Hardy et al., 2004). Thus, we operationalised resilient carers as having high life satisfaction (≥ 25; Pavot & Diener, 2008) and no depression (*n*=418). Individuals with high life satisfaction and depression, low life satisfaction (≤24; Pavot & Diener, 2008) and no depression, or low life satisfaction and depression were classified as not resilient (*n*=215).

Satisfaction with Life Scale (SWLS; Diener et al., 1985). This scale was used to measure life satisfaction. It consists of five items and is measured on 7-point Likert scales with 1=Strongly disagree to 7=Strongly agree. Although first used as a brief assessment of an individual's satisfaction with their life as a whole (Pavot & Diener, 2008), the scale has also been used to assess the subjective quality of life of people living with serious health problems. Life satisfaction is recognised as a distinct construct, but the scale is moderately correlated with measures of subjective wellbeing. This suggests that satisfied individuals are generally well-adjusted and free from psychopathology (Diener et al., 1985). The SWLS has good psychometric characteristics. Diener et al. (1985) found good test-retest reliability (.82). They factor analysed the five item scale to determine a single factor, 'global evaluations of a person's life', which accounted for 66% of variance. There was good internal consistency (item total correlations all above .61) and good face validity (SWLS correlated adequately with independent interviewer estimates of life satisfaction).

Geriatric Mental State - Automated Geriatric Examination Assisted Taxonomy (GMS-AGECAT; Copeland, Dewey, & Griffiths-Jones, 1986). This was used to assess depression. Data from a GMS examination, a semi-structured clinical interview, were inputted into the AGECAT system; a computerised algorithm used to generate diagnoses of organic states, including dementia, anxiety disorder and depression. AGECAT assesses the severity of each psychiatric condition in relation to others, in order to determine the primary diagnosis. AGECAT scores range from 0-5, with 0=no symptom, 1, 2=sub-clinical and 3, 4, 5=likely cases. We were interested in the three depression groups:

likely depression; comprising neurotic and psychotic subtypes (2%), sub-clinical depression; characterised by minor mood symptoms and some non-specific symptoms (9%), and no relevant symptomology; where no or very few depressive symptoms are present (89%). We dichotomised these into two categories to simplify the operationalisation of resilience: Depressed (11%) and not depressed (89%).

The cognitive and global properties of SWLS (Larsen, Emmons, & Diener, 1983; Pavot & Diener, 1993) and affective properties of the depression variable (Spahni et al., 2015) capture the multi-dimensional and ecological characteristics of resilient individuals better than psychological resilience, making it a more comprehensive outcome variable (Pavot & Diener, 2008).

4.3.2.2 Predictor variables

4.3.2.2.1 Individual assets

During the interview, respondents were asked a number of demographic questions including *age* and *gender* (see Table 4.1).

Social class. Respondents were asked to describe the type of work they did for their last occupation; this was an open-ended response. We then coded the responses using the British Household Panel Survey (BHPS) variable 'Registrar General's social class of most recent job'. Three social class groups, Professional/Managerial, Skilled, and Partly/Unskilled, were collapsed from the seven original BHPS categories (Soulsby, 2011). The three social class groups were dummy coded, using the modal category, Skilled, as a reference group.

Psychological Resilience. This was measured using the Psychological Resilience Scale (Windle et al., 2008). The scale includes three factors: competence/self-efficacy, interpersonal control, and self-esteem. Items were originally measured on 5-point Likert scales with 1=Strongly Disagree to 5=Strongly Agree. Higher scores indicate higher levels of psychological resilience. Windle et al. (2008) found that the reliability of the scale was .83. Prior to data reduction, Chronbach's alpha was .80 for interpersonal control; .80 for competence/self-efficacy; and .84 for self-esteem. Construct validity has gained support in three (60-69, 70-79, 80-90) out of four (50-59) age groups (Windle et al., 2010).

4.3.2.2.2 Community resources

Respondents were asked a number of questions about social networks and support from family and friends.

Frequency of family and friends. Respondents were asked: 'how often do you see any of your family/friends?' Questions were originally measured on 6-point Likert scales with 0=Never to 5=Daily. Approximately 57% of respondents reported seeing their family, and 55% seeing their friends, at least twice weekly. Less than 1% of respondents reported never seeing their family and no respondents reported never seeing their friends. We dichotomised frequency of family and friends into weekly or less (family *n*=269; friends *n*=212) and twice weekly or more (family *n*=371; friends *n*=357).

Family/Friends: Emotional support. We used the following question as a proxy for emotional support: 'how many family members/friends do you feel at

ease with to talk about private matters?' Questions were originally measured on 6-point Likert scales with 0=None to 5=Nine or more. Approximately 46% of respondents reported between two and four family members available for emotional support, and 36% of respondents reported between two and four friends available for emotional support. 12% of respondents reported having no family members and 22% of respondents reported having no friends available for emotional support. We dummy coded this variable as: None (family *n*=76; friends *n*=140), One-Two (family *n*=256; friends *n*=224), and Three or more (≥3; family *n*=306; friends *n*=204) available for emotional support.

Family/Friends: Practical support. We used the following question as a proxy for practical support: 'how many family members/friends do you feel at ease with that you could call on them to help?' Questions were originally measured on 6-point Likert scales with 0=None to 5=Nine or more. Approximately 48% of respondents reported between two and four family members, and 42% reported between two and four friends. 7% of respondents reported having no family members and 9% of respondents reported having no friends available for practical support. We dummy coded this variable as: None (family *n*=47; friends *n*=56), One-Two (family *n*=208; friends *n*=207), and Three or more (≥3; family *n*=383; friends *n*=304) available for practical support.

The latter category of each variable was used as the reference group, because i. it had the highest modal frequency for almost all of the variables, and ii. the literature posits a positive association between support and subjective wellbeing (Gaugler et al., 2007; Ross et al., 2003; Walsh, 2012).

4.3.2.2.3 Societal resources

Respondents were asked a number of questions about the social, community and health and welfare services that they engage with.

Attendance at social groups. Respondents were asked: 'do you attend meetings of any community/neighbourhood, church/mosque or social groups, such as over 60s clubs, evening classes?' This question originally had the response options of: No (47%), Yes occasionally (6%) and Yes regularly (46%), which we dichotomised into: No (47%) and Yes (53%). We view this variable as a societal resource because it measures the attendance at groups rather than functional participation.

Service use. Respondents were asked: 'In the last four weeks have you seen, or had a visit from or to, any of the following services: Home help; nursing services; chiropodist; meals on wheels; physiotherapist; occupational therapist; speech therapist; social worker; day centre; day hospital; GP?' Questions were originally measured by individual response options of Yes/No. We recoded this into a global proxy of monthly service usage by summing the number of Yes responses to each service type for each respondent.

Table 4.1: Descriptive statistics and frequencies of respondent characteristics.

Characteristics	*N*	Mean (SD)/*n*
Age	646	74 (6.60)
Gender	645	
Male		337
Female		308
Social class	632	
Professional	-	285
Partly/Unskilled	-	75
Skilled	-	272
Psychological resilience	631	27.59 (3.32)
Frequency of family	640	
≤ Weekly	-	269
≥ Twice weekly	-	371
Frequency of friends	569	
≤ Weekly	-	212
≥ Twice weekly	-	357
Family: emotional support	638	
None	-	76
One – two	-	256
≥ Three	-	306
Friends: emotional support	568	
None	-	140
One – two	-	224
≥ Three	-	204
Family: practical support	638	
None	-	47
One – two	-	208
≥ Three	-	383
Friends: practical support	567	
None	-	56
One – two	-	207
≥ Three	-	304
Social groups (Yes)	645	339
Service use	639	2.50 (1.32)

Note. Age: min.=65, max.=93; Psychological resilience: min.=15, max.=35; Service use: min.=0, max.=8. Min.=Minimum. Max.=Maximum.

4.4 Results

We conducted a hierarchical multiple logistic regression to determine the association between twelve predictors from the resilience framework (Windle & Bennett, 2011) and resilience (resilient=1; non-resilient=0) (see Table 4.2).

Individual assets (age, gender, psychological resilience and social class) were entered at step 1, followed by community resources (step 2; frequency of family/friends, emotional and practical support from family/friends) and societal resources (step 3; social groups and service use). Odds ratios (OR) and 95% confidence intervals (CIs) were calculated to describe how well each level of a variable predicted outcome in comparison with the reference group (see Figure 4.2). Only respondents providing responses to all variables were included in the analysis. Consequently, the number of scores available varied for each measure.

4.4.1 Hierarchical multiple logistic regression

The current study tested whether individual assets and community and societal resources from the resilience framework were associated with resilience in a sample of informal carers (N=646). The overall fit of step 1 (individual assets) is significant, model $\chi^2 = 59.86$, $df = 5$, $p<.001$, accounting for approximately 15% (Nagelkerke R^2) of the variance in resilience. The overall fit remains significant at step 2 (community resources), block $\chi^2 = 18.62$, $df = 10$, $p=.045$, explaining 19% of the variance in resilience (Nagelkerke R^2). Finally, the overall fit is significant at step 3 (societal resources), block $\chi^2 = 7.52$, $df = 2$, $p=.023$, explaining 21% of the variance in resilience (Nagelkerke R^2). The full model significantly predicts resilience; correctly identifying 73% of cases.

4.4.1.1 Individual assets

Psychological resilience was significantly associated with resilience. In the final model we found that respondents with high levels of psychological resilience were 1.2 times more likely (OR=1.24, CI=1.16-1.33) to be resilient. Age, gender and social class did not significantly predict resilience.

4.4.1.2 Community resources

Practical support from friends was significantly associated with resilience. In the final model we found that respondents who have between one and two friends available for practical support are less likely (OR=.54, CI=.33-.89) to be resilient than those with ≥ three friends. Frequency of contact with family, frequency of contact with friends, emotional and practical support from family, and emotional support from friends were not significantly associated with resilience.

4.4.1.3 Societal resources

Service use was significantly associated with resilience. In the final model we found that respondents who use more services are less likely to be resilient than those who use less services (OR=.83, CI=.71-.97). Attendance at social groups did not significantly predict resilience.

Table 4.2: Hierarchical Logistic Regression analysis showing full model statistics for individual assets, community and societal resources as predictors of resilience.

Variables	*B*(SE)	OR	95% CI
Individual assets			
Age	-.02(.02)	.98	.95-1.01
Gender			
Male (1)	.05(.22)	1.06	.69-1.62
Female (0)	-	-	-
Social class			
Professional	.35(.34)	1.42	.72-2.78
Partly/Unskilled	.08(.23)	1.08	.70-1.69
Skilled	-	-	-
Psychological resilience	**.22(.04)**	**1.24**	**1.16-1.33**
Community resources			
Frequency of family			
≤ Weekly (1)	-.20(.21)	.82	.54-1.24
≥ Twice weekly (0)	-	-	-
Frequency of friends			
≤ Weekly (1)	.03(.21)	1.03	.68-1.57
≥Twice weekly (0)	-	-	-
Family: emotional support			
None	.73(.39)	2.07	.97-4.43
One – two	.44(.24)	1.55	.96-2.50
≥ Three	-	-	-
Friends: emotional support			
None	-.31(.31)	.73	.40-1.33
One – two	.25(.27)	1.29	.76-2.19
≥ Three	-	-	-
Family: practical support			
None	-.29(.44)	.75	.32-1.76
One – two	-.17(.25)	.85	.52-1.39
≥ Three	-	-	-
Friends: practical support			
None	-.50(.37)	.61	.29-1.26
One – two	**-.61(.25)**	**.54**	**.33-.89**
≥ Three	-	-	-
Societal resources			
Social groups			
No (1)	-.31(.22)	.73	.48-1.11
Yes (0)	-	-	-
Service use	**-.19(.08)**	**.83**	**.71-.97**

Note. R^2 (3) = .21 (Nagelkerke R^2). Step 1 model χ^2 = 59.86, *df* = 5, *p*<.001. Step 2 block χ^2 = 18.62, *df* = 10, *p*=.045. Step 3 block χ^2 = 7.52, *df* = 2, *p*=.023. SE = Standard Error. Significant (p<.05) ORs are indicated in **bold.**

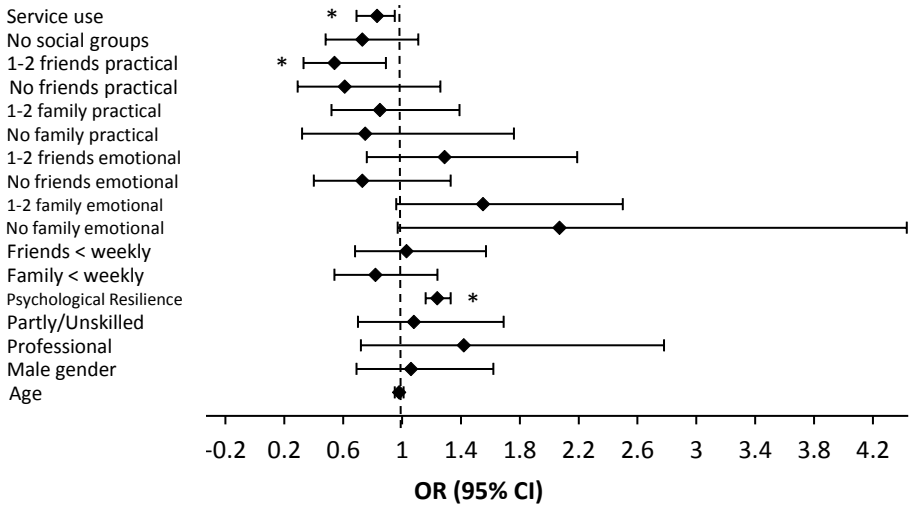

Figure 4.2: Forest plot showing the odds of being resilient at step 3 of the model (Categorical predictors are compared to their reference category: see Section 4.3.2.2. * Significant ORs, p<.05).

4.5 Discussion

The current study was conducted to assess whether individual assets and community and societal resources from the resilience framework (Windle & Bennett, 2011) were associated with resilience in a sample of older informal carers. On an individual level, we found that the odds of being resilient were increased in those who are more psychologically resilient. On a community level, the odds of being resilient were increased in those who have 3 or more friends available for practical support. On a societal level, the odds of being resilient were significantly increased in those who use fewer monthly health and welfare services.

We found that there were no gender or age differences in resilience. This is unsurprising given that demographic differences in resilience have not been consistently established in the literature. Although our previous work suggested that older spousal carers are likely to be less resilient than their younger counterparts, and men comprise a greater proportion of resilient carers than women (Donnellan et al., 2015), we did not replicate this here. This suggests that gender and age differences are more marked in spousal than informal carers in general. However, it is more likely to reflect differences in research method and sample size. For example, we did not include a young carer comparison group in the current sample. This is important because the association between high resilience and high wellbeing diminishes with increasing age (Windle et al., 2010), which could render group comparisons in an older sample non-significant. Studies show that older carers have relatively poor health status (Pinquart & Sörensen, 2007; Rosness et al., 2011) which, in turn, may moderate the effect of age on resilience, i.e. older carers with good health status may be more resilient than those with poor health status. Future research is required to investigate this further. It is likely that older carers have the capacity to be resilient, but may require additional resources in order to achieve this as they age.

There was no association between social class and resilience despite evidence to suggest that SES is associated with resilience in carers (Donnellan et al., 2015; Gaugler et al., 2007). This may be because we based social class on just one aspect of SES: previous occupation. Our results are in line with those of Gaugler et al. (2007), who found that higher income and education, but not

employment, were negatively associated with resilience in dementia carers. Practitioners and policy makers should consider that socioeconomic status variables may be differentially associated with resilience when identifying at-risk carer groups. We found that carers with high psychological resilience (competence/self-efficacy, interpersonal control and self-esteem) were more likely to achieve a resilient outcome. This complements the work of Spahni et al. (2015), which found that psychological resilience was significantly associated with resilient outcomes in widowed older adults. It also supports work that has linked life satisfaction and psychological resilience to subjective wellbeing and positive adjustment in older adults (Bennett, 2015[b]; Diener et al., 1985; Windle et al., 2010). Although there was a positive association between them, practitioners and policy makers should not assume, for example, that psychological resilience is sufficient for a resilient outcome. These potential discrepancies highlight the importance of other factors, including community and societal resources (Ungar, 2011).

At a community level, frequency of contact with family was not associated with resilience. This is not unexpected as the literature is mixed; some studies showed that larger social networks facilitate increased resilience (Gaugler et al., 2007; Ross et al., 2003), and others found that frequent contact with family members hinders resilience if it is over-intensive and causes a sense of dependency (Donnellan et al., 2015). These discrepancies may reflect differences in research methodology, as the latter took a qualitative approach. Functionally, we found that perceived access to emotional and practical support from family was not associated with resilience. This contrasts with Pinquart and

Sörensen (2000) who found that subjective wellbeing is predicted by emotional support from family. The lack of association between practical support and resilience may be because practical support emphasises the care recipient's impairment which contributes to distress and low self-efficacy (Reinhardt, Boerner, & Horowitz, 2006; Uchino, 2009). Our findings also contrast with our previous finding that family practical support may hinder resilience if it is perceived as over-intensive (Donnellan et al., 2015). The latter paper focused on spousal dementia care whereas the current paper looks at non-spousal informal carers; the type of impairment and care relationship may be important aspects to consider in future research.

We found that frequency of contact with friends was not associated with resilience. This is unexpected given that frequent contact with friends has been associated with high subjective wellbeing in older adults (Pinquart & Sörensen, 2000). Functionally, we found that access to emotional support from friends was not associated with resilience. This is surprising given that resilient carers are likely to disclose private matters to only a few close friends with shared caregiving experience (Donnellan et al., 2015). However, we did find that carers who perceive one-two friends available for practical support were less likely to be resilient than those with three or more friends. This suggests that the more friends the better when it comes to practical support. This makes intuitive sense; the nature of practical support makes it appropriate to call on more people for help. However, the constraints of our data set make it unclear whether these friends are available solely for one support type, or whether they overlap. Practical attempts to facilitate resilience could start by increasing the

number of friends for practical support. Practitioners should not just consider the structural composition of support resources, but also the functional perception of support (Deist & Greeff, 2015; Luthar, 2006; O'Rourke & Tuokko, 2000; Roth et al., 2005; Sherman et al., 2013). Indeed differences in perceived support may explain our lack of association between family and friend frequency, family function and resilience.

On a societal level, we found that attendance at social groups was not associated with resilience. This contrasts with findings that support groups facilitate resilience by providing a forum within which emotional and practical support from friends can be shared (Donnellan et al., 2015; Ferreira, Santos, & Maia, 2012; Han et al., 2014). Such groups may be especially important for non-resilient carers who may lack individual assets, or perceive family and friend networks to be structurally or functionally absent. We found that carers using more health and welfare services were less likely to be resilient than those who use fewer. This is crucial for older carers, who are more likely to have poorer health status and rely on more services (Pinquart & Sörensen, 2007; Rosness et al., 2011). Our findings contrast with studies that found health and welfare provision reduces depressive symptoms, burden, (di)stress and rates of institutionalisation in carers (Han et al., 2014; Pickard, 2004; Rosness et al., 2011). Our findings also contrast with our previous finding that carers who use services such as respite care are more likely to be resilient (Donnellan et al., 2015). The direction of the relationship between resilience and services is unclear; for example, it could be that non-resilient carers may be least likely to use certain services, or it could be that a lack of services is driving non-

resilience. In our study we did not distinguish between services or the functions they serve. This is important as some services may facilitate resilience more than others, for example, those that reduce the objective level of stressors, such as flexible in-home respite care (Pickard, 2004; Seddon et al., 2006). Our findings suggest that it is not the number of services that are important for resilience in carers; rather it is tailored services that are perceived as necessary and beneficial by the carer.

Although secondary data is useful it poses a number of methodological constraints (Kiecolt & Nathan, 1985). The study was restricted to the measures available in the CFAS Wales data set. We used a self-report question to select our carer subsample. Carer self-report can lead to unknowns; for example, care duration, number of care recipients, care intensity. Other studies typically use minimum thresholds to identify individuals as carers or non-carers, for example; a set number of Activities of Daily Living (ADLs), or a minimum number of hours per week of caregiving (Hirst, 2004). Policy makers quantify carer needs using eligibility criteria. For example, The Care Act (2014) introduced a national eligibility threshold for carers across England, based on identifying: 1. Whether a carer's needs are a consequence of providing necessary care for an adult with a physical or mental condition; 2. To what extent the carer's needs affect their ability to achieve specified outcomes, or puts their health at risk, and; 3. Whether and to what extent this impacts on their wellbeing (Department of Health, 2014). Seddon and Robinson (2015) outline two problems with the above approaches: First, caregiving is a complex process; over-reliance on criteria and thresholds constrains the varied

meanings that carers attach to their role. Second, an increasing number of individuals do not necessarily identify themselves as carers, but still look after someone who is dependent. This is especially marked in family carers, many of who continue to see themselves as spouses, children, and parents (Morbey, 2015). By classifying individuals on their own terms and de-emphasising specific stressors, we provide a potentially more representative sample of carers.

Our data set did not include an appropriate measure of resilience so we operationalised resilience using a proxy of high life satisfaction and no depression. Non-resilience was operationalised as: high life satisfaction and depression; low life satisfaction and no depression; or low life satisfaction and depression. One problem with this is that having depression does not necessarily indicate non-resilience. However, the figures were approximately in line with resilience prevalence rates from four longitudinal studies on family dementia carers (Joling et al., 2015[b]). These issues are common across the literature; carer resilience is inconsistently operationalised, and there is no 'gold standard' measure of resilience (Gaugler et al., 2007; O'Rourke et al., 2010; Ross et al., 2003; Windle et al., 2011). Resilience classification is difficult but not impossible. Critics have argued that resilience is best understood as a continuous quantitative outcome (Kalisch et al., 2015). However, Southwick, Pietrzak, Charney and Krystal (2015) argue that complex adaptive systems do not always change in a linear manner. Previously, we classified resilient carers using a number of criteria based on Bennett (2010): individuals must experience a significant challenge (i.e. caregiving); view their current life

positively; be actively participating in life; return to or maintain a life that has meaning or satisfaction; and not be distressed (Donnellan et al., 2015). The current operationalisation maps closely onto these criteria.

Despite these limitations we were able to corroborate previous findings concerning factors from each level of the resilience framework (i.e. individual; psychological resilience: community; practical support from friends: and societal; health service use). Unfortunately, we were not able to test the full resilience framework; for example, biological assets and social policies. Further research with different methods and data is required to determine the association between resilience and factors from across the full resilience framework. These variables, not least resilience, are known to vary over time (Gaugler et al., 2007; Ross et al., 2003). Future research could use CFAS Wales Wave 2 data to follow the same cohort of carers through transitions within caregiving and into other later life challenges such as institutionalisation or widowhood. From this we would gain a more comprehensive insight into the ongoing development of resilience.

In conclusion, we found that older informal carers draw on a number of individual assets, community and societal resources from across the resilience framework to facilitate resilience. Resilience transcends the individual; carers interact with others and utilise informal and formal support systems (Bonanno et al., 2007; Ungar, 2011; Wiles et al., 2012). Further work is needed to analyse the dynamic role that these resources play in facilitating or hindering resilience in carers, and indeed how they change through transitions in care status.

PART THREE

INVESTIGATING EMERGENT MECHANISMS OF RESILIENCE IN INFORMAL CARERS

Chapter 5

Exploring the age-related positivity effect in carers and non-carers across the life course[7]

5.1 Foreword

The previous Chapters identified a number of individual assets, community and societal resources that facilitate or hinder resilience in older informal carers. Further research is warranted to investigate how these factors facilitate resilience. An important psychological asset to emerge from the data was the theme of staying positive. The mechanism and theoretical framework underlying the association between positivity and resilience has not yet been tested. Previous research has examined positivity in relation to caregiving but mostly in association with caregiver burden and less as a feature of resilience. Little research combines age-related emotional processing theory with the applied topic of informal caregiving. The current study uses quasi-experimental methods to investigate whether a sample of young, middle-aged and old informal carers and non-carers demonstrate a positivity effect, and whether this effect holds when controlling for current mood and education level.

5.2 Introduction

Emotional stimuli are consistently found to selectively engage attention as well as enhance recall (Buchanan & Adolphs, 2002; Dewhurst & Parry, 2000;

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Hamann, 2001; Ochsner, 2000; Smith, Dolan, & Rugg, 2004; Talmi & Moscovitch, 2004). This is known as the Emotional Enhancement Effect (EEE; Kensinger & Corkin, 2003). Research has focused on the differences in emotional processing between younger adults and older adults (Kensinger, 2008; Mather & Knight, 2006; Spaniol, Voss, & Grady, 2008; Thomas, 2006). For younger people, the EEE often enhances attention and recall toward negative emotional stimuli, whereas older people demonstrate biased attention and recall towards positive rather than negative or neutral stimuli (Reed et al., 2014). This phenomenon has been termed the age-related positivity effect (Carstensen & Mikels, 2005; Mather & Carstensen, 2005).

A number of studies have found support for the age-related positivity effect. Charles, Mather and Carstensen (2003) found that, although older adults were least likely to recall images overall, they recalled more positive images than negative or neutral images, whereas younger adults showed equal recollection for positive and negative images. Similar findings have been established from studies using emotionally charged words (Kensinger, 2008; Spaniol et al., 2008; Thomas, 2006) as well as emotionally charged faces (Mather & Carstensen, 2003). However, some studies have found a negativity bias, rather than a full positivity effect; for example, both young and old people attend to negative more than positive stimuli (Comblain, D'Argembeau, van der Linden, & Aldenhoff, 2004; Kensinger, 2007). One explanation for this is that positive and negative stimuli hold similar arousal levels, albeit at opposite ends of the continuum (Kousta, Vinson, & Vigliocco, 2009). The positivity effect is likely to be moderated by affective variables. For example, there is evidence to

suggest that mood improves with age. Carstensen, Pasupathi, Mayr and Nesselroade (2000) sampled participants' moods at random intervals over the course of a week and found that negative mood was less prolonged in older compared to younger adults. More recently, Isaacowitz, Toner, Goren and Wilson (2008) found that younger adults demonstrated mood-congruent gaze; they looked more at positive faces when in a good mood and more at negative faces when in a bad mood. Conversely, older adults showed mood-incongruent gaze; they looked more at positive faces and away from negative faces when in a bad mood. The positivity effect in older adults may be explained by their ability to override or dissipate negative mood states more effectively than younger adults.

A key explanation of the positivity effect comes from the socioemotional selectivity theory (SES: Carstensen, 2006), which holds that adaptive motivational differences account for the discrepancies between age groups in the processing of emotional information (Carstensen, 2006; Reed et al., 2014). According to the theory, during early adulthood, individuals devote much of their time and attention toward gaining knowledge and planning for the future, in recognition of their longer time perspective. However, as they grow older, they recognise that their life perspective is shortening and so they devote more time to emotional gratification and present-oriented needs and goals (Reed et al., 2014). Therefore, attention and memory biases shift as a result of their changing priorities with chronological age (Carstensen, Isaacowitz, & Charles, 1999). There is evidence to suggest that these time perspectives are not fixed. Lynchard and Radvansky (2012) found that young people respond more

quickly to positive words when taking the perspective of an older adult, whereas older adults respond more quickly to negative words when taking the perspective of a younger adult. There are well-documented effects of age-related memory degradation (Craik, 1994) and age-related slowing of processing (Salthouse, 1996). This is important because the shift from knowledge-based and future-oriented goals towards emotionally gratifying, present-oriented goals requires sufficient cognitive resources. For example, Mather and Knight (2005) found that the positivity effect is more pronounced in older adults with higher executive functioning. Bruno, Brown, Kapucu, Marmar and Pomara (2014) found that years of education moderates the relationship between age and the positivity effect; people with fewer years of education recall significantly fewer positive words. The exact point at which emotional processing systems begin to change has not been investigated (Carstensen & Mikels, 2005). The absence of a middle-aged cohort in the literature means a large part of the life course is overlooked in relation to emotional processing, which may provide insight into when and why this emotional processing discrepancy occurs (Charles et al., 2003).

It is important to study how systems of emotional processing operate under different conditions, for example, during adverse major life events. Informal caregiving is a high probability event; the proportion of dependent to independent people is increasing, and people are living longer with complex health and social care needs (Bond & Cabrero, 2007). The physical and psychological consequences for carers are well-documented (Pinquart & Sörensen, 2003[a]; Pinquart & Sörensen, 2007; Sörensen et al., 2002). According

to SES, carers should not elicit a positivity effect as individuals need to be able to pursue goals without external interference (Reed & Carstensen, 2012). Conversely, if positivity is explained by constrained time perspectives and subsequent reprioritisation towards present-oriented needs and goals, then caregiving could be constraining these time horizons even further. In a recent review, Roth, Fredman and Haley (2015) found that carers experience reduced mortality and extended longevity compared to non-carers. Many carers report little or no caregiving-related strain, and most report benefits of caregiving. Carers are a heterogeneous group; some find caregiving burdensome, whereas others do not. This finding formed the basis of Folkman's (1997) seminal work on coping with severe stress. In a longitudinal study of AIDS carers, she established that positive psychological states coexisted with negative psychological states throughout caregiving and bereavement. Coping processes that generate positive emotions include: benefit finding and reminding, adaptive goal processes, reordering priorities and infusing ordinary events with positive meaning (Folkman, 2008). It is acknowledged that these positive coping mechanisms are not an appendage to stress, but a co-occurring and distinct entity (Folkman, 2008).

Staying positive has several beneficial functions for carers: positive cognitions, such as optimism (Zauszniewski et al., 2009), enjoyment (Pinquart & Sörensen, 2003[b]) and fulfilment (Cohen et al., 2002), buffer against sources of burden and depression. Sharing a joke can maintain companionship (Murray et al., 1999), reciprocity (Voelkl, 1998) and the care recipient's sense of identity (Hellström et al., 2005). Our own qualitative research with spousal dementia

carers shows that many carers stay positive despite the physical, emotional, social and financial stressors associated with informal care; positivity is an important facilitator of resilience (Donnellan et al., 2015; Etters et al., 2008). Resilience has been defined as: "The process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity" (Windle, 2011; p. 163). Koole et al. (2015) suggest that psychological adaptation is best served by maintaining a steady emotional balance. Bennett (2010) operationalises resilient carers as viewing their current life as positive. Thus, the positivity effect may function as the mechanism by which carers stay positive to facilitate resilience against the adversity of caregiving (Carstensen & Fredrickson, 1998; Carstensen & Mikels, 2005; Donnellan et al., 2015). We are unaware of any existing research that has examined the positivity effect in carers.

Emotional processing research traditionally focuses on early and late adulthood, and carer resilience work typically focuses on later life (Windle & Bennett, 2011), yet it is a relevant concept across the life span. It is not uncommon for children and young adults to provide significant care to a parent (Dearden & Becker, 2004), and yet relatively little work has focused on carer resilience in young adulthood (Windle & Bennett, 2011). This is important because early caregiving experiences can influence the capacity for future resilience (Shifren, 2008). Many other carers are of working age, caring for children with complex needs, spouses in middle-age, or parents (Windle & Bennett, 2011). Ross et al. (2003) found that middle-aged carers who

experienced the benefits of caregiving, including personal satisfaction and fulfilment, were more likely to be resilient. Carers can be positive and resilient in mid-life as well as in early and late life. More research is needed to examine the age-related positivity effect in carers and non-carers across the life course.

5.2.1 Aims and hypotheses

The current study aims to investigate whether a sample of young, middle-aged and old informal carers and non-carers demonstrate a positivity effect. If this is the case, it may explain carer's tendency to stay positive in their role despite the challenges typically associated with caregiving. We test the following four hypotheses:

1. Word recall will decrease with increasing age; young participants will recall most words, followed by middle-aged, and old.
2. Emotional words will be recalled more than neutral words by all age groups.
3. The old age group will show a positivity effect; recalling more positive than negative words, and the young age group will recall more negative than positive words.
4. There will be a difference in recall of emotional words between carers and non-carers.

We are interested in examining whether these effects hold when controlling for education level and current mood, as research shows that pre-existing age differences in mood (Carstensen et al., 2000; Isaacowitz et al., 2008) and education (Bruno et al., 2014; Mather & Knight, 2005) may confound the age-

related positivity effect.

5.3 Methods

5.3.1 Participants

159 participants were purposively recruited into the following categories: young (18-28; *n*=44), middle-aged (40-60; *n*=58) and old (65-75; *n*=57). Carers were defined as anyone who self-identified as currently providing care to a sick or frail relative (ONS, 2011[b]). Self-report is a standard method of classifying carers, used by British Household Panel survey (Hirst, 2004) and the 2011 UK Census (ONS, 2011[b]). By classifying individuals on their own terms and de-emphasising specific stressors, we provide a potentially more representative sample of carers. The only exclusion criterion was that participants must not self-report any major clinical condition, psychiatric disorder, or cognitive impairment. No participants were excluded on this basis.

All participants were recruited from the Merseyside and Wirral areas of North West England. Young carers and non-carers were recruited from the campus of the University of Liverpool. A proportion of young carers were recruited from a small network of other contacts. Middle-aged, old carers and non-carers were recruited through a number of organisations, including luncheon clubs, community and carer support groups. Some carer data were missing so the number of percentage scores available varied for each measure; for example, care recipient and diagnosis data. Further participant characteristics can be found in Table 5.1.

Table 5.1: Descriptive statistics and frequencies of participant characteristics.

Characteristics	*N*	Mean (±)/*n* (%) Young	Middle-aged	Old
Non-carers (N=84)				
Gender				
Women	84	19 (68%)	15 (54%)	14 (50%)
Men		9 (32%)	13 (46%)	14 (50%)
Age (years)	84	20.46 (1.77)	49.36 (6.49)	67.82 (2.60)
Current mood[1]	84	4.79 (1.17)	5.32 (1.19)	4.61 (1.17)
Years of education[2]	84	8.41 (1.42)	7.82 (3.28)	6.46 (1.35)
Carers (N=75)				
Gender				
Women	75	12 (75%)	23 (77%)	18 (62%)
Men		4 (25%)	7 (23%)	11 (38%)
Age (years)	75	22.75 (3.47)	49.20 (6.01)	74.03 (5.65)
Current mood	75	4.75 (1.18)	5.63 (1.27)	4.93 (1.25)
Years of education	72	7.50 (3.93)	6.68 (2.84)	5.11 (1.60)
Care recipient	75			
Spouse		-	3 (10%)	24 (83%)
Parent		5 (31%)	21 (70%)	-
Child		1 (6%)	4 (13%)	1 (3%)
Other relative[3]		7 (44%)	2 (7%)	4 (14%)
Diagnosis	75			
Dementia		2 (13%)	13 (43%)	14 (48%)
Cancer		1 (6%)	4 (13%)	1 (3%)
Learning difficulties		5 (31%)	1 (3%)	-
Psychological disorder		2 (13%)	3 (10%)	2 (7%)
Other[4]		4 (25%)	5 (17%)	5 (17%)
Care duration (years)	75	4.41 (2.28)	5.03 (5.51)	7.95 (7.25)
Care intensity				
Rarely (1-2 days a week)	75	2 (13%)	3 (10%)	2 (7%)
Occasionally (3-4)		4 (25%)	7 (23%)	-
Most of the time (4-5)		7 (44%)	9 (30%)	3 (10%)
All of the time (6-7)		3 (18%)	11 (37%)	24 (83%)

Key: [1] 1 (very sad) – 7 (very happy). [2] Measured from Secondary School onwards. [3] e.g. Nephew/niece; aunt/uncle; sibling; grandchildren; grandparents. [4] e.g. Alcoholism; communication disorder; developmental disorder.

5.3.2 Design and materials

The study uses an ex post facto design; a quasi-experimental research method in which pre-existing groups are compared on a dependent variable (Lammers & Badia, 2005). The independent variables are: word type (positive, negative,

neutral); age (young, middle-aged, old); and care status (carer, non-carer). The dependent variable is number of words recalled.

Words were selected from the Affective Norms for English Words (ANEW) database (Bradley & Lang, 1999), and balanced for length (short to long, e.g. JOY - PUNISHMENT), frequency (rarely to often, e.g. REALITY - LAUGHTER), mean arousal (calm to excited, e.g. PART - DANGER) and mean valence (pleasant to unpleasant, e.g. WARMTH - MURDERER). Neutral words were related to the abstract concepts of 'think' and 'mind' (e.g. OPINION) so that the semantic relatedness of emotional words did not lead to any mnemonic advantages (Kensinger, 2008). We ensured that an even balance of low, medium and high mean rated words were used in the final word list. Words were presented on A4 word cards, printed in Calibri headings, size 96 font, and capitalised for clarity. The testing booklet contained an information sheet, consent form, and demographic information sheet including age, gender, years of education and current mood. For carers the booklet collected information on care duration and intensity, as well as care recipient information, including relationship and diagnosis type. This was followed by the distractor task, a blank recall sheet, and debrief sheet (see Appendix 5).

5.3.3 Procedure

All participants who expressed interest in the study were asked to report any major clinical condition, psychiatric disorder or cognitive impairment that might inhibit performance. No participants were excluded on this basis. The study was conducted in a quiet isolated room. After establishing informed consent (see Appendix 4), participants were asked a number of questions to

establish demographic information. Participants were required to specify their age and gender and the number of years of education that they had completed from Secondary School onwards. They were then asked to indicate their current mood on a Likert scale of 1 (very bad) to 7 (very good). Carers were asked about carer information at this stage. Education and mood were recoded into categorical independent variables after the study. We created three discrete education levels; compulsory (lowest score through five years); further (5.1 – seven) and higher (7.1 through highest score). We dichotomised current mood using a median split, with scores ≤ 4.9 recoded as low, and scores ≥ five recoded as high.

Participants were told that they would be presented with a list of 30 words, but not that they varied in emotional valence. Their task was to respond to a 'shallow' or 'deep' processing question after each word was presented; participants were not told that this was a distractor task at this stage. 'Shallow' questions asked participants to state how many letters were in the word. 'Deep' processing questions asked participants how many times they came across the word in the space of a week. Each question provided 4-point Likert scale response options. To avoid ceiling or floor effects, young participants were given three seconds, middle-aged five seconds and old seven seconds to identify each word and answer the corresponding question. Participants were not permitted any extra time to complete this task. These time limits were based on a previous study by Murray and Kensinger (2013), and our own pilot study which indicated that older participants needed more time to complete the distractor task. The presentation order of words and processing questions was

pseudo-randomised and counterbalanced to control for primacy and recency effects.

After completing the distractor task for all 30 words, participants were given a surprise free recall task of listing as many words as they could remember from the list. It was essential that this aspect of the study was hidden as Löckenhoff and Carstensen (2007) found that the positivity effect was lost when participants were notified of the free recall component. Participants were assured that spelling was not important and that there were no time constraints. Finally, participants were fully debriefed and thanked for their time. This procedure was used for all age groups and both care statuses. All participants were asked if they had friends, family or associates who might also be interested in participating. If so they were given an information sheet and expression of interest form to pass on. The study received ethical approval from the University of Liverpool Research Governance Committee (see Appendix 2).

5.4 Results

The current study investigated whether a sample of young, middle-aged and old informal carers and non-carers demonstrate a positivity effect, and whether any effect held after controlling for education level and current mood. Descriptive statistics can be found in Table 5.2.

A three-way mixed ANOVA was conducted on word type, age and care status. Box's test of equality of covariance was not violated (p>.001). Where sphericity had been violated, results were interpreted using the Greenhouse-Geisser correction. Post hoc tests using Bonferroni pairwise comparisons were

conducted on significant results, including mean difference (MD) and standard errors (SE).

Table 5.2: Descriptive statistics of word recall by age group and care status.

		N	Mean (±)		
			Positive	Negative	Neutral
Young	Non-carer	28	3.68 (1.28)	3.54 (1.62)	2.75 (.93)
	Carer	16	3.06 (1.77)	3.50 (1.21)	1.87 (1.54)
Middle-aged	Non-carer	28	2.82 (1.22)	2.86 (1.33)	2.29 (1.12)
	Carer	30	2.73 (1.23)	2.33 (1.32)	1.53 (1.01)
Old	Non-carer	28	3.18 (1.49)	2.46 (1.00)	1.14 (.76)
	Carer	29	2.86 (1.48)	1.55 (1.02)	1.03 (1.09)

We found a significant main effect of word type on word recall, $F(1.87, 285.60) = 45.38$, $p<.001$, $\eta_p^2 = .23$. Pairwise comparisons revealed that participants recalled significantly more positive (MD=1.29, SE=.15), $p<.001$) and negative words (MD=.94, SE=.12, $p<.001$) than neutral words. Positive and negative words did not significantly differ in recall (MD=.35, SE=.15, $p=.067$).

We found a significant main effect of age on word recall, $F(2, 153) = 22.01$, $p<.001$, $\eta_p^2 = .22$. Pairwise comparisons showed that young participants recalled significantly more words than middle-aged participants (MD=.64, SE=.16, $p<.001$), and old participants (MD=1.03, SE=.16, $p<.001$). Middle-aged recalled significantly more words than old participants (MD=.39, SE=.14, $p=.02$). We found a significant main effect of care status on word recall, $F(1, 153) = 14.64$, $p<.001$, $\eta_p^2 = .09$, with non-carers recalling more words than carers.

We found a significant age by word type interaction on word recall, $F(3.73, 285.60) = 4.44$, $p=.002$, $\eta_p^2 = .06$ (see Figure 5.1). Young, middle-aged

and old participants consistently recalled more emotional words than neutral words. Pairwise comparisons revealed a positivity bias in old participants, as they recalled significantly more positive than negative words (MD=1.01, SE=.25, p<.001). Although young participants recalled more negative than positive words, the difference was not significant (MD=.15, SE=.29, p=1.00). Middle-aged participants recalled more positive than negative words, but the difference was not significant (MD=.18, SE=.25, p=1.00).

There was no significant word type and care status interaction, as non-carers consistently recalled more words overall. There were no significant interactions between word type, age and care status, or between age and care status. Finally, we examined whether these effects held after controlling for education level and current mood. We used a five-way ANOVA, with word type, age, care status, education level and current mood as independent variables. We did not find any unexpected interactions between education level, current mood and any of the other variables (p>.05). Education level and current mood are unlikely to have a confounding effect on our findings.

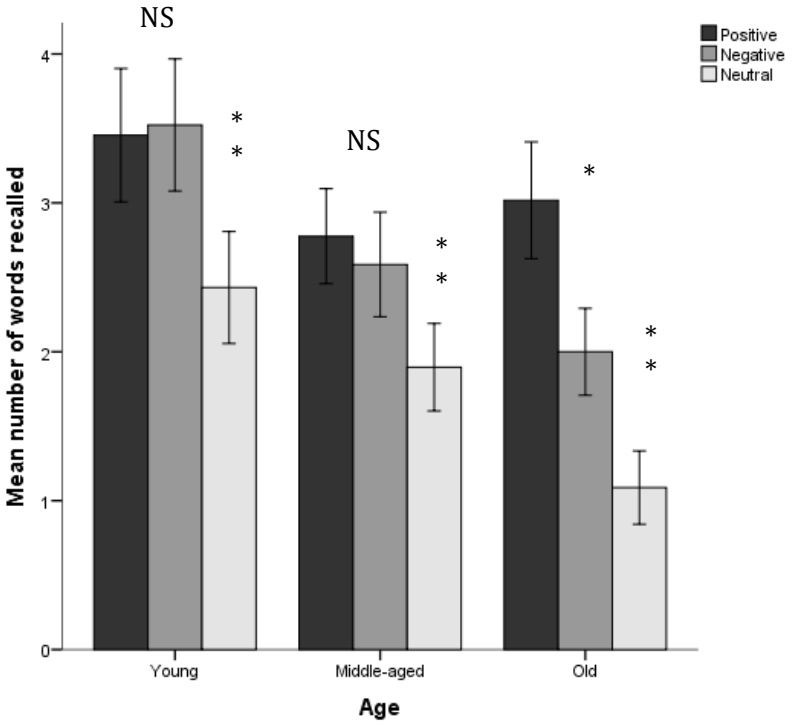

Figure 5.1: Clustered bar chart showing interaction between age and word type (NS=Not significant. * p<.05. Error bars represent standard errors).

5.5 Discussion

The current study aimed to investigate whether a sample of young, middle-aged and old informal carers and non-carers demonstrate a positivity effect, and whether any effect held after controlling for education level and current mood. Overall we found that young people recalled more words than middle-aged and old people, which supports the first hypothesis and the well-documented effect of age-related memory degradation and slowing of processing (Craik, 1994; Salthouse, 1996). In accordance with hypothesis 2, we found an EEE: emotional words were recalled more than neutral words across all age groups and both care statuses, suggesting that it is a robust effect across the life course (Buchanan & Adolphs, 2002; Dewhurst & Parry, 2000; Hamann, 2001;

Kensinger & Corkin, 2003; Ochsner, 2000; Smith et al., 2004; Talmi & Moscovitch, 2004). Finally, we found a positivity bias in the old group, but not in the young or middle-aged group, offering partial support to hypothesis 3, and previous studies that found a full positivity effect (Charles et al., 2003; Kensinger, 2008; Mather & Carstesen, 2003; Spaniol et al., 2008; Thomas, 2006). There were no interactions between word type, age and care status, or age and care status. There were no unexpected interactions between education level and any of the other variables. This suggests that education level and current mood are unlikely to have a confounding effect on our findings.

Our findings contrast with those that either failed to establish a recall discrepancy between emotional word types (Kousta et al., 2009), and those finding a negativity bias independent of age (Comblain et al., 2004; Kensinger, 2007). Our findings can be explained by the SES; the old group may be demonstrating a positivity bias as a result of their goal-directed behaviours changing as they transition into late adulthood (Carstensen et al., 1999; Reed et al., 2014). Although the middle-aged group display recall patterns more similar to the old than young group, they may not yet be experiencing a sense of their time horizons shortening. Although this fills a literature gap on mid-life emotional processing (Carstensen & Mikels, 2005), future research is needed to systematically examine age segments between middle and old age to determine the precise point at which a positivity effect originates, as well as which other factors may be underlying it (Charles et al., 2003).

We did not find a significant difference in recall of emotional words between carers and non-carers, and so hypothesis 4 must be rejected. This can

be explained in terms of SES theory: the challenge of caregiving interferes with the pursuit of emotional gratification and present-oriented needs and goals (Reed & Carstensen, 2012; Reed et al., 2014). However, the fact that we established a positivity bias despite our sample comprising 47% carers is interesting, given research shows that carers are more likely than non-carers to experience stress, depressive symptoms (Joling et al., 2010; Pinquart & Sörensen, 2003[b]; Shah & Wadoo, 2010), lower levels of subjective wellbeing and self-efficacy (Pinquart & Sörensen, 2003[b]). We found that carers recalled significantly fewer words than non-carers overall. This may reflect the negative psychological consequences of caregiving, including burden and depression (Pinquart & Sörensen, 2003[a]). There is some evidence to suggest that the chronic stress of spousal dementia caregiving is associated with significant cognitive decline compared to similar non-carer controls (Vitaliano et al., 2005). More research is needed to draw out the implications of these findings.

Exploratory post hoc analysis of the old adult positivity bias revealed that it was most pronounced in carers as opposed to non-carers. Although old carers recall fewer words, they recall significantly more positive than negative words compared to old non-carers. This would support Folkman's (1997) notion that positive psychological states co-occur with negative psychological states. It could suggest that there is something specific about carers that make them more positive than non-carers; they could be drawing on resilience resources, e.g. positive cognitions, such as optimism (Zauszniewski et al., 2009), enjoyment (Pinquart & Sörensen, 2003[b]), fulfilment (Cohen et al., 2002), and benefit finding (Folkman, 2008; Roth et al., 2015). It is worth noting that this

interaction was not significant overall, so caution is needed when interpreting these exploratory analyses.

The current study has a number of methodological limitations. The sample sizes in some carer subgroups are small, e.g. young carers=18. It could be argued that this reflects demography; there are fewer young carers than middle-aged and old carers living in the UK (ONS, 2011[a]). The carer inclusion criteria, 'anyone who self-identifies as currently providing care to a sick or frail relative', may have been too broad, resulting in a heterogeneous sample of carers including carers of people with very different health problems. This is problematic because varied health conditions are likely to differentially affect carer experience; for example, dementia caregiving is significantly more stressful than non-dementia caregiving (Bertrand et al., 2006). It also makes characterising the degree and stressfulness of caregiving difficult. Further research with an increased sample size and a more specified sample of carers, e.g. dementia carers providing a minimum threshold of care, is necessary. Indeed, this may reveal some of the non-significant trends that we discussed previously.

Future research is needed to measure resilience in relation to the positivity effect. One would expect resilient carers to elicit a significantly higher positivity bias (Bennett, 2010; Carstensen & Fredrickson, 1998; Carstensen & Mikels, 2005; Donnellan et al., 2015). Unfortunately there is no 'gold standard' measurement tool for resilience (Windle & Bennett, 2011). Future research should examine the effect of ageing and care status transitions on the positivity effect. For example, research shows that former carers, defined as those who

"experience an episode of caring in the past that ended with the death of their dependant" (Larkin, 2009; p. 1029), experience negative psychological consequences during initial bereavement (Jenkinson, 2004), followed by more positive reconstruction later on. There are age-specific challenges that could threaten positivity, such as loss of skills and employment experience in young and middle-aged adults (Jenkinson, 2004). Mid-life transitions are also important; the middle-aged carers in our sample may be more likely to be caring for multiple people across multiple generations (Grundy & Henretta, 2006; Windle & Bennett, 2011); for example, children and parents simultaneously. This increased care challenge could be exacerbating middle-aged carer's capacity for positivity or resilience. Our data shows that middle-aged are most demographically similar to old carers in terms of impairment type, care intensity and word recall, although old carers provide greatest care intensity overall. Conversely, young carers provide care to a wider range of care recipients and impairment types. They also provide lower care intensity, and show an opposite pattern of word recall. There are less clear age differences for non-carers. Future research should address whether controlling for some of these complex demographic age differences alters the findings.

In conclusion, we found people display a clear emotional enhancement effect across the life course, within and without caregiving. We found that older people display a positivity bias in relation to the young and middle-aged, and there is some evidence to suggest that this is most pronounced in older carers. These findings do not appear to be confounded by education level of current mood. Future research is needed to clearly measure resilience in relation to the

positivity effect. Future work should further investigate ageing and care status transitions in order to examine the point at which these age-related emotional processing discrepancies originate.

Chapter 6

Family close but friends closer: Exploring social support and resilience in older spousal dementia carers[8]

6.1 Foreword

A key finding to emerge from part two was that resilient carers were well-supported by family but especially friends, with whom they shared this knowledge. Research indicates that dementia carers have unique support needs (Roth et al., 2005), but little research examines the mechanisms through which family and friend support facilitates resilience in these carers. The current study builds on these findings and uses qualitative data from chapter 3 to explore the availability, function and perceived functional aspects of support and resilience in older spousal dementia carers.

6.2 Introduction

Dementia carers have unique support needs (Roth et al., 2005): they are likely to suffer declines in the availability of people to provide informal support over time (Clay, Roth, Wadley, & Haley, 2008), and disengage from their existing social networks as they devote more time to caring as the disease progresses (Han et al., 2014; Hough, Magnan, Templin, & Gadelrab, 2005). Social networks are defined as: "the structural character of social relationships, such as the number of contacts we have or how often we spend time with those people" (Soulsby & Bennett, 2015: p. 110). Approximately 27 per cent of primary carers

[8] This Chapter was accepted for publication in Aging & Mental Health on 01/07/2016 (Manuscript ID: CAMH-2016-0087.R1).

are providing care to a spouse (NHS, 2010). Spousal carers are supported by pre-existing informal social networks (Antonucci, Birditt, Sherman, & Trinh, 2011), such as adult children, close relatives, friends and neighbours (NHS, 2010). We are unaware of any existing research that examines the types of support these people provide, nor how this support is perceived by spousal carers.

Social support has been defined as: "a transactional process whereby our relationships provide a platform for the exchange of emotional and practical support" (Soulsby & Bennett, 2015: p. 110)[9]. Sherbourne and Stewart (1991) identified five distinct dimensions of social support: emotional (positive affect, empathic understanding); affectionate (expression of love); informational (advice, guidance, feedback); tangible (practical assistance); and positive social interaction (availability of others to do fun things together). The effect of social support depends on the outcome and group being investigated. Research on older adults shows that emotional support protects cognitive functioning more than tangible support (Ellwardt et al., 2013). Pinquart and Sörensen (2000) suggest that tangible and informational support may buffer the influence of stress on subjective wellbeing. Research on carers by Han et al. (2014) shows that affectionate support and positive social interaction reduces psychological burden and the prevalence of major depressive disorder, and tangible support reduces non-psychological burden. It seems that carers benefit from a wide variety of support functions. However, there is a lack of research addressing the effect of support on resilience in carers.

[9] Cheng et al. (2016) note that carers emphasise mostly emotional support from family and friends, but not other types of support.

Resilience is defined as: "the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or 'bouncing back' in the face of adversity" (Windle, 2011: p. 163). The mere availability of close social ties, such as family members, does not simply facilitate resilience (Sherman et al., 2013); carers reject networks if they are perceived as unhelpful (Ellwardt et al., 2013; Roth et al., 2005). Thetford et al. (2015) suggested that resilience is facilitated not by the presence/absence of resources, but by the interaction of the individual with their environment.

Windle and Bennett (2011) developed an ecological resilience framework applied to carers, which posits that each carer draws on individual assets, community and societal resources which interact to facilitate or hinder resilience. Resilience is based on the principle that the majority of people cannot be resilient without facilitative interpersonal and socio-environmental factors (Bennett & Windle, 2015; Liebenberg & Ungar, 2009). In our previous work we used a three-stage hybrid method to explore the resilience resources that spousal dementia carers draw on (see Donnellan et al., 2015, for a detailed summary). We first approached the data using grounded theory, next we identified participants as resilient or not resilient. We used the following criteria: i. There must be a significant challenge: caregiving; ii. No sign of distress; iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back); iv. Actively participating in life (a sign of managing); v. Current life seen as positive (a sign of adaptation) (adapted from Bennett, 2010). Finally, we

identified the factors which facilitated or hindered resilience, and whether they could be mapped onto Windle and Bennett's (2011) framework.

We found that the availability of friend networks was almost always associated with resilience. However the picture was different for family members; they were not always sufficient to facilitate resilience. Indeed they hindered resilience if they created feelings of over-dependence (Donnellan et al., 2015). This complexity is reflected in the literature. Fiori, Antonucci and Cortina (2006) found that the absence of friends, but not family, increases depressive symptomology, and the quality of support mediates that relationship. According to socioemotional selectivity theory, the most important social contacts are aligned with the individual's self-concept and personal circumstances (Carstensen, 1991; Farran et al., *2*004). Research has shown that subjective wellbeing is predicted by emotionally close ties with adult children and frequency of contact with friends. Frequent contact with family and close ties with friends does not predict subjective wellbeing (Pinquart & Sörensen, 2000). Rosenmayr (1983) found 'intimacy at a distance'; older adults perceive their family relationships as important but wish to remain independent from them (Ingersoll-Dayton et al., 1997). This may be because seeing family regularly is likely to involve negative social exchanges and reflect increasing care demands (Pinquart & Sörensen, 2000).

Although there are several important resources and outcomes associated with and resulting from resilience, in this paper we look to further explore social support as a community resource and resilience in older spousal dementia carers. The first research objective is to identify the availability and

function of support offered to resilient and non-resilient older spousal dementia carers by their family and friends. The second research objective is to identify the perceived functional aspects of support from family and friends, and examine how this varies between resilient and non-resilient participants.

6.3 Methods

6.3.1 Participants

We purposively sampled 16 women and seven men (N=23) from two dementia support groups (n=17) and a care home (n=6) in North West England (see Donnellan et al., 2015). Three interviews have been added to this study that were not transcribed in time for inclusion in the previous study (see Table 6.1). Participants had been caring for their spouse for between two and ten years (mean = 5.44 ± 2.64) and had been married for between 28 and 61 years (mean = 49.61 ± 7.14). Age ranged from 62 to 89 (mean = 75 ± 7.46). All participants were retired. No information was available regarding how long participants had been participating in the support groups. Most participants currently lived with and cared for their spouse at home although three were already widowed (Mrs L., Mr Gr., Mrs Wk.) and another had admitted her husband into nursing home care (Mrs G.). Social class was measured by asking participants to describe the type of work they did for their last occupation. Three social class groups, Professional, Skilled, and Partly/Unskilled, were used from seven original British Household Panel Survey categories. The social class of the participants was broadly representative of similar demographics in the British population (ONS, 2011[a]).

Table 6.1: Demographic characteristics and resilience classification of carers.

Carers (N=23)	Age (years)	Marriage duration (years)	Care duration (years)	Social class	Resilient/Not resilient
Mrs W.	62	28	3	Skilled	Not resilient
Mrs C.	68	48	9	Skilled	Resilient
Mrs Wi.	69	51	4	Skilled	Not resilient
Mrs F.	71	51	3	Unskilled	Not resilient
Mrs L.*	73	53	10	Unskilled	Resilient
Mr G.	81	52	5	Skilled	Resilient
Mrs G.**	82	49	5	Skilled	Not resilient
Mrs Go.	69	40	5	Unskilled	Resilient
Mrs O.	77	59	2	Unskilled	Not resilient
Mrs S.	86	61	6	Unskilled	Not resilient
Mr Go.	74	52	10	Skilled	Resilient
Mr Wh.	71	50	10	Skilled	Resilient
Mr H.	81	53	5	Skilled	Not resilient
Mrs P.	75	49	4	Skilled	Not resilient
Mr N.	71	41	7	Skilled	Resilient
Mr Gr.*	88	56	9	Skilled	Not resilient
Mrs H.	89	58	7	Skilled	Not resilient
Mrs La.	83	55	2.5	Professional	Not resilient
Mr Ha.	80	52	3	Professional	Resilient
Mrs Cl.	69	49	3	Unskilled	Not resilient
Mrs Wk.* Ł	72	44	4	Professional	Resilient
Mrs Lg. Ł	69	43	6	Professional	Resilient
Mrs Hn. Ł	65	47	2.5	Unskilled	Not resilient

Key: *Widowed **Institutionalised Ł New participant

6.3.2 The interview

Semi-structured interviews, lasting between 25 – 90 minutes, were conducted and audio-recorded in a quiet room at each of the aforementioned venues. Each participant was interviewed on a one-to-one basis by either the first author or by one of two assistants. Data were transcribed by the first author and a transcription assistant. An open chronological and retrospective approach was used to trace feelings and events to specific stages of the participant's life, pre- and post-dementia. Section A began with factual questions: age, marriage, care duration and employment (see Appendix 8). Section B asked about life before

caregiving. Participants were prompted to describe a typical day, relationship quality, and the type of support received and how it is perceived. Section C asked about the period surrounding diagnosis or first suspicions of impairment and their initial emotional and behavioural responses. Section D asked about the present situation, repeating section B's questions. Finally participants were asked which advice they would give to someone in the same position as themselves. The study received ethical approval from the University of Liverpool Research Governance Committee (see Appendix 1).

6.3.3 Method of analysis

We adapted the three-stage hybrid method from our previous study (Donnellan et al., 2015) to re-analyse our data. Existing resilience classifications were used:

1. We used a grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995) to read and code the interviews. All references to support were coded line-by-line and focused codes were then developed, before identifying the most common themes across all interviews.
2. We re-read the interviews to identify the function of support provided and which network members provided it (see Appendix 16). Support functions were identified using Sherbourne and Stewart's (1991) dimensions of support: emotional; affectionate; informational; tangible; and positive social interaction. For example, Mrs Wk.'s neighbour mowed her lawn. This was identified as tangible support. Support availability was assessed by how many participants mentioned access to each network member. We then compared availability and function of

support across resilient and non-resilient participants. This indicated which support members and functions were associated with resilience.

3. Finally, we re-examined the codes from stage one in order to explore participant's perception of support highlighted at stage 2. For example, some participants had tangible support from children available to them, but felt that their taking control was unhelpful. We examined how this varied between resilient and non-resilient participants. This indicated whether the relationship between support and resilience was straightforward or more complex.

This process was conducted independently and blind by each author. A consensus was reached on the most prominent findings across each analysis.

6.4 Results

Although the research questions and process of analysis are sequential (see Methods), we integrate them in our reporting of results. The structure of each section is based on the frequency of support available from each network member, from highest to lowest. We use parentheses in order to clearly identify each support function within the quotes.

6.4.1 Family support

6.4.1.1 Children

Participants spoke of support from biological and, in one case, step-children. There are no functional differences between these subtypes so they are collapsed for the purposes of this analysis. There is a clear gendering of support

as daughters provide: tangible, emotional, informational and affectionate support, whereas sons provide mainly tangible support:

> I was lucky because… I had two boys and two girls, and to give me a break the girls used to take me out for the day [positive social interaction] and the boys used to look after their dad [tangible]… so we worked as a team. (Mrs L. Resilient)

> [Son 1]… is very practical [tangible] and he came here the other night and I just gave him a list. He comes and says, "what else do you need, Mother?" And [Son 2] will do all the financial stuff [tangible] for me. (Mrs La. Not resilient)

Men carers garner more support than women carers generally, especially from their daughters:

> [Daughter] knew who to contact [informational]… and she's always there if I need anything [emotional/tangible]. Every day that she's at home she calls even if it's only for half an hour but she comes to make sure everything's alright [emotional/tangible]. (Mr Wh. Resilient)

There is no difference between resilient and non-resilient participants in the availability or function of support from children; it is equally wide ranging. This suggests that support function is not always sufficient to facilitate resilience. Non-resilience could be explained by the participant's perception of support from children. Both resilient and non-resilient participants prefer 'intimacy at a distance'; child support is valued but not over-intensive to maintain independence. What distinguishes them is that non-resilient participants are

more likely to resist their children's over-involvement and justify it in terms of their competing demands. This may explain why child support does not always facilitate resilience:

> I try not to involve them [daughter] too much cause, as I say, they've got their own lives. (Mrs H. Not resilient)

> I didn't tell them [daughter and son] a lot of the things that were going on because they had their own problems, their own families to see to. (Mrs G. Not resilient)

> Last night she [daughter] rang me and she said if I wasn't working I'd come and, you know, help you and I said but you're working. (Mrs S. Not resilient)

6.4.1.2 In-laws

Participants mainly spoke of support from children-, siblings- and parents-in-law. It is worth noting that the availability of children-in-law is dependent on the availability of children. Here we focus on the functional aspects of those in-laws regardless of this structural complexity. We found that in-law support is rarely available and includes a relatively narrower range of support functions, including tangible support and positive social interaction. This is the case for resilient and non-resilient participants:

> His brother and sister… the last couple of weeks they've been coming and he loves just having them there, just chatting, and, you know, put some music on and things [positive social interaction]. That gets us through the day basically. (Mrs C. Resilient)

> [Son-in-law] showers me three times a week [tangible]…Very good of him really cause he works as well. (Mr H. Not resilient)

In addition to caring for his wife, Mr H. is physically disabled. It is unclear whether his non-resilience is related to his disability. There are no functional differences in in-law support between resilient and non-resilient participants; both are equally narrow. Again the participant's perception of in-law support could be explaining non-resilience. Non-resilient participants are more likely to resist over-involvement and explain it with competing demands:

> His Sister's always saying, "how's [Husband]?", oh he's driving me mad, "well you should give me a ring and we'll come up" [tangible] but they've got their own lives… why should they be burdened? He's my responsibility. I married him for better for worse and that's how it's gonna be. (Mrs Go. Resilient)

> We don't encourage them [in-laws] to come up to be honest because he doesn't like visitors. Well, it's not that he doesn't like people, he loves people. (Mrs W. Not resilient)

6.4.1.3 Grandchildren

Participants mainly spoke of grandchildren and great-grandchildren. This category mostly comprises younger grandchildren, as opposed to adult grandchildren. We found that grandchildren are available more to non-resilient participants, providing mainly positive social interaction and affectionate support:

> I can go out, they play outside, I can watch them. I love being in their company [affectionate] because it's a break and I'm talking totally different conversation; they will talk to you whereas [Husband] doesn't speak [positive social interaction]. I am glad when they come but I'm shattered when they've gone. (Mrs F. Not resilient)

The increased availability of support from grandchildren in non-resilient participants could suggest that grandchildren may not be sufficient to facilitate resilience. Interestingly, while there is evidence that non-resilient participants are more likely to prefer 'intimacy at a distance', they do not actively resist involvement of grandchildren as they do with children and in-laws:

> I enjoy my grandchildren like you should do but, well, in small doses [laughs]. The 15 year old is not much use really… [Husband] just hasn't the patience to deal with children. (Mrs W. Not resilient)

6.4.2 Support from friends

6.4.2.1 Group friends

Participants referred to friendships made either as a direct result of dementia, such as carer support groups, or more longstanding friendships established in other settings such as community groups or the Church. We found that group friends provide a wide range of support functions to resilient and non-resilient participants, including: emotional, informational support and positive social interaction:

> There's a little discussion group along the road full of very friendly people… it gets us out and he [Husband] likes watching… I don't know if he listens but he watches the expressions and sees people laughing [positive social interaction]. (Mrs Lg. Resilient)

> I'm in an international Christian group which is good because not only do you have spiritual direction but you have the group supporting you [emotional]… they come out with whatever's hurting them and you're there to listen and they do the same for you [positive social interaction]. (Mrs La. Not resilient)

Support group friends provide the widest variety of support functions and shared experience. This is the case for resilient and non-resilient participants:

> We are like family [affectionate]. We know each other's troubles; we exchange sad stories or glad stories every week… I think that's why I'm so stable because I talk to so many people who are in the same boat [emotional]. You don't sit there and feel sorry for yourself and you see there are ways and things to do which can keep your life quite nice. And I do them. We do them. They tell you where this is, where that is, where to get help from [informational]. (Mrs Lg. Resilient)

> The girls here [support group], we've all got one another's phone numbers. We don't socialise as such but we know we're there for one another. If one of us is at home and they're having a bad day they can always ring one of the girls up and have a chat [emotional]. (Mrs Wi. Not resilient)

> It's only when you come to the Carer's [support group] and share that you realise that yeah it's okay to explode, it's okay to cry, you know, cause they're going through… the same [emotional]. (Mrs Wi. Not resilient)

Despite receiving a wide variety of support and shared experience from group friends, there are participants who are not resilient. The evidence shows that non-resilient participants are more likely to use group friends for positive social interaction, whereas resilient participants are more likely to use them for informational support.

6.4.2.2 Existing friends

Participants talked about friends established before dementia diagnosis, for example; former co-workers or married friends. Some participants explain that existing friends have been a source of long-term support, mainly emotional support and positive social interaction. Although we found no difference in the availability of existing friends between the resilient and non-resilient, resilient participants were more likely to receive emotional and positive social interaction from those with shared experience:

> Every now and then we meet up and go for a drink and laugh at stuff we did in the old days [positive social interaction]. That helps to take away the tension of what you're going through [emotional]. (Mr N. Resilient)

> I suppose for emotional support… [Existing friend], her mother died two years ago and she was very close to her mum erm and my mum died a bit

> before that so we had a bit in common there. Erm, but she knew [husband] very well as well. (Mrs Wk. Resilient)

Existing friends with shared experience may facilitate resilience more than friends without. Conversely, existing friends of non-resilient participants seem to share less experience, and serve a narrower function, specifically positive social interaction:

> I've known her for donkeys years, 50 years, and now we meet up every few weeks and we go for a meal [positive social interaction]… around tea time-ish. (Mrs P. Not resilient)

> Our friends [existing friend 1] and [existing friend 2]… they take us out for a meal [positive social interaction]. I mean they're terrific with [husband] and it's just a little bit of relief for me. They come on holiday with us as well [positive social interaction]… they're marvellous. (Mrs Cl. Not resilient)

Interestingly, non-resilient participants are relatively more likely to have existing friends that they do not see. Participants talk about how existing friends have 'dropped out' since their spouse developed dementia:

> People drop out, you know, friends. They don't fall out with you but you can tell they're not in. There's nothing for them anymore. You've got no conversation and they've got their own lives and their own friends and that's a bit hard. So you are a bit isolated. (Mrs H. Not resilient)

> I've lost all my friends that I had before, before he got diagnosed with this. You wouldn't believe. Your friends sort of cross over the road and

> you wouldn't think they would cross over the road rather than talk to you face to face. (Mrs Hn. Not resilient)
>
> I think people are frightened if it's mental illness. If my husband had cancer or a broken leg… people would visit and I think it scares people off. That's sad. (Mrs P. Not resilient)

Indeed, some non-resilient participants explain that the reason they have drifted apart from existing friends is because they do not share an understanding of what it is like to be a carer:

> The different groups you go to, the people you meet, they become your family and friends… people don't understand unless they're living with someone with Alzheimer's and you can't expect them to understand because you wouldn't in the same position. (Mrs P. Not resilient)
>
> I met one woman that I've not seen for a long time and I said to her that my husband's got dementia… and she said, "oh I do feel sorry for you", and I thought no you don't… It was only then when it hit me that she doesn't know how I feel. Her husband's fine, you know, she's getting on with her life. (Mrs F. Not resilient)

6.4.2.3 Neighbours

We found that neighbours are available more to resilient participants, providing mainly tangible support.

> [Husband] and [Neighbour 1] used to take it in turns to do the whole lawn [tangible]. I woke up one morning and my tyre was completely flat

> so [Neighbour 2] I know he will come and do that [tangible]. (Mrs Wk. Resilient)
>
> A couple of lads who live in this street, they're only 33, and when she went missing once, they ran these streets looking for her [tangible]. (Mr N. Resilient)

Although neighbours provide only tangible support, it is clear that they facilitate resilience. Neighbour support is specialised in that it provides a crisis management function; carers can call on their neighbours in an emergency when family and other friends are unavailable. This makes neighbours a uniquely valuable resilience resource.

6.5 Discussion

Our first research objective was to identify the availability and function of support offered to resilient and non-resilient older spousal dementia carers by their family and friends. With the exception of neighbours, we found that resilient carers were no more likely than non-resilient carers to have family and friend support available to them. Family and friends served a range of functions[10]. Although children, existing friends and group friends provided a wider range of support than in-laws, grandchildren and neighbours, most were equal across resilient and non-resilient carers. Generally speaking, resilient and non-resilient carers have structurally and functionally similar support characteristics; non-resilient carers are no less likely to receive support. This suggests that social support is not always sufficient to facilitate resilience. This

[10] This does not support the work of Cheng et al. (2016), who found that family and friend support serves a narrow function, primarily emotional support.

is in line with previous findings that the mere presence/absence of resources, such as close social ties, does not simply facilitate carer resilience (Sherman et al., 2013; Thetford et al., 2015). These findings can be explained by qualitative differences in the carer's perceived satisfaction with support and their interaction with the social network (Ellwardt et al., 2013; O'Rourke & Tuokko, 2000; Roth et al., 2005).

The second research objective was to identify the perceived functional aspects of support from family and friends, and examine how this varies between resilient and non-resilient participants. Most carers, whether resilient or not, spontaneously and consistently demonstrated 'intimacy at a distance' when discussing support functions from children, in-laws and grandchildren; they perceive them as important but wish to remain independent from them (Ingersoll-Dayton et al., 1997; Rosenmayr, 1983). This complements the notion that support resources facilitate resilience up until a point, after which they become hindering (Donnellan et al., 2015). Non-resilient carers were more likely to act on 'intimacy at a distance' by resisting over-involvement of children and in-laws, and justify it in terms of their competing demands. One explanation is that seeing family regularly is likely to involve negative social exchanges and reflect increasing care demands (Pinquart & Sörensen, 2000). Tangible support may also emphasise the care recipient's impairment (Reinhardt et al., 2006) and contribute to distress and low self-efficacy (Uchino, 2009). 'Intimacy at a distance' may be more damaging for non-resilient carers if they have fewer alternative individual and societal resources from the resilience framework (Windle & Bennett, 2011). An abundance of support resources could indicate

resilience, but it could indicate non-resilience if the resources do not match current need. Non-resilient carers may be at increased risk of isolating themselves from family members. We recommend that family support be made available on the carer's own terms as not to relinquish their feelings of independence and autonomy. These perceptions may moderate the effect of family support on resilience in older spousal dementia carers.

Resilient carers were more likely to receive informational support from group and existing friends with shared experience. Conversely, friends of non-resilient carers seem to share less experience, and serve a narrower function; such as positive social interaction. This suggests that shared experience may facilitate resilience. Socioemotional selectivity theory predicts that support perceived as congruent with the carer's self-concept and personal circumstances is especially beneficial for subjective wellbeing (Carstensen, 1991; Farran et al., 2004). Our findings emphasise the importance of clubs, church groups and support groups as societal resources within which individual and community resources can be shared. Indeed, research shows that support groups can increase emotional and informational dimensions of support, and reduce psychological distress, depressive mood and burden (Han et al., 2014).

Existing friends were more likely to disengage from non-resilient carers (Clay et al., 2008). Again, shared experience may explain this; they have little in common anymore. We suggest that friends with common ground share more understanding and are therefore perceived as more supportive than friends without common ground. Harris (2013) suggested that friendships are best maintained in the context of dementia through understanding, accepting and

recognising the person's values and limitations. It may be that carers play their own role in actively disengaging from their friends over time (Han et al., 2014; Hough et al., 2005). Spencer and Pahl (2006) note that longstanding friends are relatively multi-faceted compared to new friends and this may cause differences in the type of support offered and the way it is perceived. Existing friend support varies pre- and post-dementia whereas family support is more stable over time. Other supports, such as group friends, are gained. Practical attempts to reduce loneliness or increase the number of social relationships may be futile; practitioners and policy makers should not rely solely on the presence or absence of support networks but the perceived satisfaction with social support (O'Rourke & Tuokko, 2000; Thetford et al., 2015). These perceptions may moderate the effect of friend support on resilience.

Unexpectedly we found that grandchildren were more available to non-resilient carers. They provided mainly positive social interaction and affectionate support; a relatively narrow and lower level function than, for instance, support from children. This may simply reflect age-differences between participants; non-resilient are slightly older than resilient participants so may have older and more capable grandchildren. Positive social interaction and affectionate support from grandchildren may be too narrow and low level to facilitate resilience. These functions could explain why carers prefer 'intimacy at a distance', but do not actively resist support from grandchildren as they do children and in-laws. Positive social interaction and affectionate support from grandchildren may be less likely than tangible support from children and in-laws to threaten the carer's sense of independence. Most of the

grandchildren in the study are younger, and so they are also less likely to have competing demands that carers can use to justify this resistance. Further research is needed to explore these findings in more detail. Differences in availability make it difficult to assess functional differences between resilient and non-resilient carers. We found that neighbours were more available to resilient carers. Neighbours were qualitatively different from friends; they were not identified as friends by carers. However neighbour support was functionally unique; they provided tangible crisis management at times when family and close friends were unavailable (Toot et al., 2013). It was clear that this reduced feelings of burden and stress (Han et al., 2014). The findings suggest that supportive neighbourhoods and neighbours are essential resilience resources for dementia carers.

A key strength of the current study is that we included relatively unstudied social network members; for example, in-laws and neighbours. There are unique functional differences between each support member. Previous studies have suggested that spousal carers are supported mostly by pre-existing social networks (Antonucci et al., 2011). We show that carers can gain support over time, such as group friends. Our in-depth qualitative methodology is another strength. It allows us to capture the complex dynamic processes of social support, and ground social networks within a richer context. This informs future qualitative and quantitative work to draw out the theoretical and practical implications established in this paper. However, qualitative research precludes causality; directionality between support and resilience cannot be assumed. We have shown that family and friend support

serves a range of specific functions which facilitate or hinder resilience. However, there are examples in our data where the social interactions of resilient carers are targeted towards shared experience and informational support. Non-resilient carers may actively disengage from existing friends, and resist family support which is over-intensive. This fits with the resilience framework (Windle & Bennett, 2011) which posits that resources facilitate resilience which then feeds back to create further challenges and resources. Further discussion of directionality goes beyond the research objectives of this study. More research is needed to explore these complex mechanisms of support and resilience.

There are a number of other important considerations. 17 participants were sampled from dementia support groups whereas six were from a care home. This has implications for social support; perhaps some of our sample is supported differently than other carers. Future research should look to recruit a more representative sample. Spousal carers are often not the only primary carer. Future research may wish to interview carer dyads; for example, wife-daughter caring for father, or husband-neighbour caring for wife. Research has examined parental dyads when the mother has dementia (Ward-Griffin, 2007), but no research has studied these from the perspective of the carer. This may uncover hidden dimensions of the dyadic relationship. Due to the unpredictable course and extended duration of dementia (Potgieter et al., 2012), future studies may wish to examine the longitudinal effects of social support in carers. Most longitudinal studies in this area use quantitative approaches (Gaugler et al., 2007; Ross et al., 2003) but qualitative longitudinal research in this area is

complex and rare (Calman, Brunton, & Molassiotis, 2013). By following the same cohort of carers and interviewing them through transitions into institutionalisation or widowhood using the resilience framework (Windle & Bennett, 2011), we would gain a more dynamic picture of support in carers.

In conclusion, our findings suggest that social support is not a straightforward resilience resource. Family and friends provide a range of supports to older spousal dementia carers but it is not always sufficient to facilitate resilience. Support functions may facilitate resilience only if they are perceived to match need. We recommend that carers should be supported by appropriately involved family members that foster independence and like-minded friends with shared interests, ideally within a group setting where expertise and experience can be acquired and shared. The findings bridge the gap between individual and community dimensions of the resilience framework (Windle & Bennett, 2011), although more work is needed to address the complex relationship between support and resilience Future research should acknowledge the full structural composition of support, and the multi-dimensional function it serves for carers over time.

Chapter 7

How does resilience change over time and care status in spousal dementia carers? A qualitative longitudinal study[11]

7.1 Foreword

Chapter 3 identified resilient and non-resilient carers, and used an ecological framework to identify a number of resources which facilitated or hindered resilience (Donnellan et al., 2015). However, these findings were cross-sectional and little research examines how resources facilitate resilience through care status transitions. More longitudinal research is necessary to assess the ongoing development of resilience over time. The current study builds on chapter 3 findings by using qualitative longitudinal follow-up data to examine spousal dementia carers' capacity to be resilient over time and across care status, and to identify which assets and resources are associated with these resilience and care status transitions.

7.2 Introduction

Spousal carers experience gradual increases in stressors over time (Goldstein, Atkins, Landau, Brown, & Leigh, 2006; Kramer, 2000). These are associated with impaired resilience to stress, negatively impacting: health; quality of life; relationship satisfaction; and social support (Lavretsky, Siddarth, & Irwin, 2010; O'Connor & McCabe, 2011). However, there are individual differences in response to these stressors. In a study of spousal carers, O'Connor and McCabe

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(2011) found no changes over time in quality of life, mood, marital satisfaction, or social support. Dementia carers often report stability or even decreases over time on outcomes such as depression, role overload and role captivity (Gaugler et al., 2000). Carers can be resilient in the face of increasing adversity:

> "The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or 'bouncing back' in the face of adversity" (Windle, 2011: p. 163).

Windle and Bennett (2011) developed an ecological resilience framework; carers draws on individual assets, community and societal resources which interact to facilitate or hinder resilience. Previously we used a three-stage hybrid method to explore the resources that facilitate or hinder resilience in spousal dementia carers (Donnellan et al., 2015). 8/20 participants were resilient. A resilient carer typically stayed positive and actively maintained their relationship and loved one's former self. Resilient carers were knowledgeable and well supported by family, but especially friends, with whom they shared this knowledge (Donnellan, Bennett, & Soulsby, 2016).

7.2.1 Longitudinal changes in carer resilience

Research shows that carer resilience changes over time. Gaugler et al. (2000) found that longer care duration is associated with better psychological adaptation in carers. O'Rourke et al. (2010) operationalised psychological resilience as: perceived control; commitment to living; and favouring challenge

versus stability. These components were differentially associated with depressive symptoms in spousal dementia carers over time. Baseline control and challenge were associated with reduced depressive symptoms at one-year follow-up. Commitment to living did not predict depressive symptoms over time. Psychological resilience is distinct from but associated with the outcome of resilience (Bennett, 2015[b]). Spahni et al. (2015) found that psychological resilience and pre-existing relationship quality predicted the outcome of resilience in bereaved spouses. The caregiving context is dynamic; carers transition in and out of caregiving. For spousal carers, this is often through institutionalisation or death of the care recipient.

7.2.2 Resilience in the face of care status transitions

Institutionalisation and death of the care recipient have negative physical and psychological effects on the carer (Bond, Clark, & Davies, 2003; Schulz, Williamson, Morycz, & Biegel, 1991). However the picture is not straightforward. Kramer (2000) found that stressors decreased and wellbeing remained stable in male carers who institutionalised their wives. Despite stressors increasing, wellbeing increased in those who continued to care at home. Both groups appraised stressors as less stressful. This suggests that continuing home carers adapt better over time. Stephens, Kinney and Ogrocki (1991) found that institutionalisation of the care recipient alleviates time constraints, leading to enhanced social support resources, fewer restrictions in social activities and greater satisfaction with social and leisure activities. Gaugler et al. (2007) found that carers with low baseline resilience were more likely to have institutionalised the care recipient, but less likely to experience a

care recipient death, three years later. Carer resilience is unlikely to cause care recipient death, but may protect against institutionalisation of the care recipient. We are unaware of any research that explores whether institutionalisation facilitates resilience in carers.

Widowed former carers may be more resilient than widowed non-carers. Bennett (2010) found that some widowers who had been caring for their wives had practical skills (e.g. cooking, cleaning) and personal characteristics (e.g. stoicism) that facilitated their resilience throughout bereavement and widowhood. This may be explained by anticipatory grief: experiencing phases of normal bereavement in advance of the loss of the care recipient (Garland et al., 2012). Anticipatory grief may relieve some of the burden or distress associated with caregiving (Schulz et al., 2006), independent of depressive symptoms in the carer and behaviour problems of the care recipient (Holley & Mast, 2009). We are unaware of any research that examines whether anticipatory grief facilitates resilience in carers.

There is evidence that widowed former carers are more resilient than continuing home carers. In a prospective study of former dementia carers, Schulz et al. (2003) found that continuing home carers were relatively more likely to experience a range of stressors, including depressive symptoms, and end of or reduction in paid employment. Conversely, widowed former carers experienced fewer depressive symptoms within three months post-bereavement, and reductions to below baseline within one year post-bereavement. Widowed former carers may have a greater capacity to be resilient as the bereavement leads to a reduction in caregiving stressors (Schulz

et al., 2003). However, these studies do not fully capture the changing nature of resilience over time.

Larkin (2009) found that widowed former carers pass through a 'post-caring trajectory'. First, individuals experience the 'post-caring void'; negative emotional experiences and a reduction in contact with formal services (Jenkinson, 2004). Individuals then begin to change routines and take part in 'closure tasks'. Finally, individuals reconstruct their lives post-caring by rebuilding social relationships and pursuing leisure interests or life-long ambitions. However, these phases are unlikely to be linear or fixed in duration. Mausbach et al. (2007) found that dementia carers experienced immediate improvement in burden and mastery following institutionalisation or death of the care recipient. There was an immediate reduction in depressive symptoms following institutionalisation. In a longitudinal study of spousal dementia carers, Bond et al. (2003) found that continuing home carers experienced stable quality of life. Widowed former carers and those who institutionalised their spouse ('yielders') experienced improved quality of life, mental health and perceived health status. They could be compensating for the social isolation of continuing home care. Social activities increased in both groups, which may be explained by functional relief of caregiving responsibilities. Despite this functional relief, 'yielders' experienced only minor increases in psychological wellbeing. Care status transitions may differentially facilitate resilience in spousal dementia carers over time. As Bennett (2010) suggests, the time has to be right to achieve resilience.

7.2.3 Rationale and research objectives

The resilience framework (Windle & Bennett, 2011) has not been tested longitudinally. This is important given the unpredictable symptomology and extended course of dementia (Potgieter et al., 2012). Longitudinal studies typically use quantitative approaches which rarely distinguish between different types of former carer and ignore their personal experiences (Gaugler et al., 2007; Ross et al., 2003). Qualitative longitudinal research in this area is complex and rare (Calman et al., 2013); for instance, Larkin (2009)'s work on the post-caring trajectory is one of the only studies to qualitatively explore the experiences of former carers. There is little emphasis on the assets and resources associated with carer resilience over time and across care status transitions. The aim of qualitative longitudinal research is "to generate rich data and a deeper understanding of people's experiences including how and why these change over time" (Casey, Murphy, Lawton, Findlay-White, & Dinneen, 2011; p. 4). This approach helps us to address the aims of this study. The current study uses qualitative longitudinal methods to follow the care status transitions of 13 current and former spousal dementia carers: continuing home carers, former carers (institutionalised), and former carers (widowed). We address the following research objectives: i. To examine spousal dementia carers' capacity to be resilient over time and across care status, and ii. To identify which assets and resources are associated with these resilience and care status transitions.

7.3 Methods

7.3.1 Participants

7.3.1.1 Original sample

We purposively sampled 23 current and former spousal dementia carers. Most participants lived with and cared for their spouse at home although three were already widowed (Mrs L., Mr Gr., Mrs Wk.) and another had admitted her husband into a nursing home (Mrs G.). Participants were recruited from two dementia support groups and a care home in North West England. The first author made contact with staff at each of the organisations by phone, before being invited to give a brief talk about the research. The socioeconomic status distribution of the participants was representative of the British population (ONS, 2011[a]). The first author kept in touch with each of the original participants so that they could be followed-up in a timely and appropriate way. No pre-arrangement was made at this stage due to the unpredictable nature of dementia care (Potgieter et al., 2012).

7.3.1.2 Follow-up

Participants were followed up by phone between 1.5-3 years after the original interview. The follow-up period varied as we could only interview participants at their own convenience. Nine women and four men were willing to be re-interviewed: a retention rate of approximately 57%. This exceeds the minimum theme saturation threshold of 12 interviews; the point at which no new information or themes are observed in qualitative data (Guest et al., 2006). One participant was now deceased, one withdrew due to poor health, and three

were widowed at Time 1 (T1) so were not followed up. An additional five participants were not traceable. Each member of the follow-up sample had been caring for their spouse for between 3 and 13 years (mean = 7.42 ± 3.05) and had been married for between 31 and 60 years (mean = 50.08 ± 7.42). Age ranged from 65 to 85 (mean = 75.38 ± 6.54). Only participants providing care at home or those who had institutionalised their spouse at T1 were followed up.

Participants fell into one of three care pathways: continuing home carers (n=5/13), former carers (institutionalised; n=3/13) and former carers (widowed; n=5/13). All carer institutionalisation occurred two years before Time 2 interviews commenced. Widowed carers had been widowed for between eight months and two years (mean=1.5 ± 7.80). We considered marriage duration to have ceased if the care recipient died and care duration to cease if the care recipient was institutionalised.

Table 7.1: Participant characteristics (years) and resilience classification at follow-up (N=13).

Carers	Age	Marriage duration	Care duration	Follow-up	Pathway	Classification Time 1	Classification Time 2
Mrs W.	65	31	4	3	Inst.	NR	R
Mrs C.	71	50	11	3	Widowed	R	R
Mrs Wi.	72	54	6	3	Inst.	NR	NR
Mr G.	84	55	8	3	Home	R	R
Mrs G.	85	50	6	3	Widowed	NR	R
Mrs Go.	72	42	7	3	Widowed	R	NR
Mrs O.	80	60	3	3	Widowed	NR	R
Mr Go.	77	55	13	3	Home	R	R
Mr Wh.	74	52	12	3	Widowed	R	R
Mr H.	84	56	8	3	Home	NR	NR
Mrs P.	78	52	6	2	Inst.	NR	R
Mrs Lg.	71	45	8	1.5	Home	R	R
Mrs Hn.	67	49	4.5	1.5	Home	NR	NR

Key: R=Resilient. NR=Not resilient. Home=Continuing home carer. Inst.=Former carer (institutionalised). Widowed=Former carer (widowed).

7.3.2 The Interviews

7.3.2.1 Time 1

The original interviews were digitally recorded during monthly carer meetings. All interviews were semi-structured and conducted either by the first author or by one of two female research assistants. Interviews took place in a private room, and lasted between 25 – 90 minutes. Interviews took an open chronological and retrospective approach to allow feelings and events to be traced to specific stages within the care duration (see Appendix 8). See Donnellan et al. (2015) for a detailed summary of the interview structure.

7.3.2.2 Time 2

Follow-up interviews (T2) were conducted by the first author at the participant's home and lasted between 30 minutes – two hours. All started with a recapitulation of key themes from T1. The questions that followed were tailored to individual care statuses to capture the unique experiences of each participant. Continuing home care interviews asked about general changes since the last interview and about the present time. Participants were asked to describe a typical day spent alone and with their spouse, relationship quality, division of responsibility and type and amount of support given and received (see Appendix 9).

Former carer interviews asked about events leading up to the institutionalisation or death of the spouse, including their initial emotional and behavioural reactions. Participants were asked to describe a typical day, how their responsibilities had changed, and whether there had been changes in

support. Participants were given the opportunity to talk about anything that they felt we had missed. Finally, participants were prompted to provide advice to other people in similar circumstances as themselves (see Appendix 10).The study received ethical approval from the University of Liverpool Research Governance Committee. All identifying features have been anonymised in the quotations used (See Appendix 1).

7.3.3 Method of analysis

We used a three-stage hybrid method in our analysis of the original and follow-up data (see Bennett, 2010; Donnellan et al., 2015). In our original study, we used a grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995) to read and code the interviews (see Appendix 12). We then classified the participants as resilient or not, using the criteria below. Finally we determined which factors were associated with resilience using the ecological framework (Windle & Bennett, 2011; see appendix 13).

Holland, Thomson and Henderson (2006) proposed that qualitative longitudinal research should involve an initial cross-sectional within-time analysis followed by a longitudinal between-time analysis. In line with this, we reflexively re-coded T1 interviews using the same method as above in order to refamiliarise with the data and identify whether any new themes had emerged. If any new codes emerged they were merged with the existing codes from Donnellan et al. (2015). The following summarises the follow-up analysis in detail:

1. We read through each T2 interview in its entirety. Interviews were reflexively coded line-by-line and focused codes were developed, before identifying themes based on all interviews (see Appendix 14).
2. Then, we re-read T2 interviews to identify participants as resilient or not. Each author classified each participant independently. This was done blind without knowledge of T1 classifications. We used the same criteria as before:
    i. There must be a significant challenge: caregiving.
    ii. No sign of (di)stress.
    iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back).
    iv. Actively participating in life (a sign of managing).
    v. Current life seen as positive (a sign of adaptation).
3. Finally, we reanalysed T1 and T2 codes to examine the factors associated with stable and changed resilience classification and care status transitions (see Appendix 15).

7.4 Results

7.4.1 Classification

Our first research objective was to examine spousal dementia carers' capacity for resilience over time and across care status. Five participants remained resilient (stable resilient), three remained non-resilient (stable non-resilient) and four participants became resilient (non-resilient to resilient). Only one

participant became non-resilient at T2 (resilient to non-resilient). Thus there are overall gains in resilience over time.

Continuing home carers comprise only stable participants: three stable resilient and two stable non-resilient. Former carers (institutionalised) include two who change from non-resilient to resilient, and one stable non-resilient participant. Of the five widowed former carers, two remained resilient, two became resilient, and one became non-resilient (see Table 7.2).

Table 7.2: Stable and changed resilience classifications across care status over time.

Pathway (1.5 – 3 years)	Resilience classification over time			
	Stable resilient	Non-resilient to resilient	Stable non-resilient	Resilient to non-resilient
Continuing home carer	Mr Go.; Mr G.; Mrs Lg.		Mr H.; Mrs Hn.	
Former carer (institutionalised)		Mrs P.; Mrs W.	Mrs Wi.	
Former carer (widowed)	Mrs C.; Mr Wh.	Mrs G.; Mrs O.		Mrs Go.

Key: Stable resilient (resilient at T1 and T2); Non resilient to resilient (non-resilient at T1, resilient at T2); Stable non-resilient (non-resilient at T1 and T2); Resilient to non-resilient (resilient at T1, non-resilient at T2).

7.4.2 Assets and resources associated with resilience and care status transitions

Our second research objective was to identify which assets and resources are associated with resilience and care status transitions. The following section

highlights the assets and resources associated with resilience under each care status pathway. We try to present one T1 quote followed by a T2 quote from the same participant throughout.

7.4.2.1 Continuing home carers

7.4.2.1.1 Stable resilient

These participants are characterised by continuing individual assets and community resources. The majority of these participants remain resilient despite all noting the deteriorating health of their spouse. A key individual asset is the ability to stay positive:

> I'm positive. I laugh and I sing and she laughs... I've even said to one of the neighbours about my singing and she says, "[Mr Go.], it's a good job we've got a detached house". (Mr Go. T1)

> I try to get into her head and say, are you happy? I know she's not sad, she's happy, and I'm happy as well. (Mr Go. T2)

Another individual asset is a continued desire to keep the care recipient stimulated and give life more meaning:

> We often go to [park] before we go to [activity group]… If there is anything on at a museum we go there. I do the best I can to keep him out and to keep him stimulated. (Mrs Lg. T1)

> Monday we're going to a wild flower centre… Tuesday will be [support group] for him. Wednesday will be a little discussion group along the road… In between that he likes to see his cousin, we go to see my sister,

> our daughter comes or we go to see her. So we have a very full life. (Mrs Lg. T2)

These participants have community resources such as support group friends. These are highly valued for their enduring shared experience and informational support:

> We are like family. We know each other's troubles; we exchange sad stories or glad stories every week… I think that's why I'm so stable because I talk to so many people who are in the same boat. (Mrs Lg. T1)

> Meeting all the people, nattering… is just so good for your soul. It's great… we're all in the same boat and we all would help each other if we could… people are very friendly… you find out all sorts of things. (Mrs Lg. T2)

7.4.2.1.2 Stable non-resilient

These participants have continuing characteristics over time. For some, stable non-resilience reflects the declining function of the care recipient. Focusing on aspects that have become lost or irreparably changed is typical of non-resilience:

> He will say to me sometimes, "you don't love me, do you?", and I'll say of course I love you. (Mrs Hn. T1)

> He just doesn't bother with me at all now... He actually swears at me which he never would have done before. (Mrs Hn. T2)

For others, stable non-resilience is characterised by a continued resigned attitude:

> Everything is at a standstill now. It's just a matter of waiting until something happens… there's no future. (Mr H. T1)

> It's not going to improve… it can only go one way, it can only get worse. (Mr H. T2)

7.4.2.2 Former carers (institutionalised)

7.4.2.2.1 Stable non-resilient

Only participants who were non-resilient at T1 institutionalised their spouse. Stable non-resilient participants are characterised by continuing negative emotions, such as anger and guilt:

> It's me just feeling a bit guilty I suppose… I seem to be more angry cause he can't put things together. (Mrs Wi. T1)

> I went to the garden centre… and I went, oh, I should be there [visiting husband] instead of here sat drinking this cup. I felt guilty. (Mrs Wi. T2; institutionalised spouse two years ago)

7.4.2.2.2 Non-resilient to resilient

These participants become resilient in the face of admitting their spouse into a care facility. They now have more time to spend pursuing their hobbies and interests:

> We were both members of the gym… but last August I decided to join again. I wouldn't have done that if he was at home. (Mrs W. T2; institutionalised spouse 2 years ago)

On a community level, Mrs W. now enjoys more time socialising with family:

> I've got a daughter and two granddaughters… They come every Thursday for their tea which is very nice because it got to the stage where I wasn't really seeing them. (Mrs W. T2; institutionalised spouse two years ago)

Some participants previously had longstanding friends who they could not see often. They now spend their free time doing new things and meeting new people:

> I do have a couple of friends… just keep in touch on the phone really and occasionally meet up… I have a couple of friends who I can't go and see now. (Mrs P. T1)

> We went to the Lowry to see Farewell to Arms. Bit heavy but I enjoyed the day and met people I hadn't before. (Mrs P. T2; institutionalised spouse two years ago)

These participants experienced negative emotions which were exacerbated by the institutionalisation of their spouse. On a societal level, participants manage this stress through health service use:

> Every time I open my mouth I seem to say something wrong… it makes you feel unhappy all the time. (Mrs W. T1)

> I went to see a counsellor for five weeks. She was brilliant… We talked about things I've never talked about before and she said, "turn the guilt into regret"… That really was the turning point. (Mrs W. T2; institutionalised spouse two years ago)

Some participants now take the opportunity to volunteer and 'give back' to other people in similar circumstances:

> It took me a long time to go out and do that originally [volunteering] but I do think it's vital that anybody does join and get involved. (Mrs P. T2; institutionalised spouse two years ago)

7.4.2.3 Former carers (widowed)

7.4.2.3.1 Resilient to non-resilient

Only one participant changed from resilient to non-resilient. Following the death of her husband, Mrs Go. loses key psychological assets that she had before:

> I have changed… My confidence in doing things and going places has gone. (Mrs Go. T2; widowed for one year)

Initially, Mrs Go. was able to rationalise the negative emotions associated with being a carer. However she develops more negative emotional characteristics after the death of her husband, such as guilt:

> I do get upset and sad at times… but it's life, isn't it? You've just got to get on with it. (Mrs Go. T1)

> I feel guilty… that I should have done more for him. (Mrs Go. T2; widowed for one year)

7.4.2.3.2 Stable resilient

These participants remain resilient following the death of their spouse. These participants are characterised by an ability to maintain continuity. They maintain aspects of the care recipient's former self despite their death:

> He's still got a brilliant sense of humour at times. (Mrs C. T1)

> [Husband] changed a lot of people's perception of Alzheimer's… I never thought it took [husband] away. (Mrs C. T2; widowed for two years)

Family support is valued in these participants, especially from daughters. The nature of this continued social support changes pre- and post-bereavement:

> I've got a daughter who's a nurse… she knew who to contact… Every day that she's at home… she calls to make sure everything's alright. (Mr Wh. T1)

> The daughter said… "We've booked this holiday in Scotland. You're coming with us". So we had a trip to Scotland… it was better cause you were doing something all the time. (Mr Wh. T2; widowed for one year)

These participants have gained individual assets, such as free time to pursue their leisure interests:

> I've just started going out again… come Summer I'll be out on the bowling green. (Mr Wh. T2; widowed for one year)

> When I have a holiday now I can honestly relax and enjoy it… I've done like two cruises on my own… I'm fine when I'm with people. (Mrs C. T2; widowed for two years)

After becoming widowed, Mrs C. documented her caregiving experiences in a book which she then sold to a local charity. This had a therapeutic effect on her bereavement experience:

> I felt as though he was still with me. I felt it got me through a lot… I wanted to get all those memories down so I could revisit them. (Mrs C. T2; widowed for two years)

7.4.2.3.3 Non-resilient to resilient

Negative emotion is reduced when the spouse dies, and participants develop more resources. On an individual level, some participants have now accepted their circumstances:

> It's a lot better now because I've realised, don't be stupid, you're on your own, you're your own boss. (Mrs G. T2; widowed for 2 years)

Over time, Mrs G. goes from feeling lonely to spending more time pursuing her hobbies:

> I never see anybody other than when I go out shopping. (Mrs G. T1)

> I go out for a half hour music lesson twice a week now… That's my relaxation, you know, because I love music. (Mrs G. T2; widowed for two years)

In summary, the findings suggest that resilience is more likely to remain stable than change over time. The majority of those who continue to provide care in the home remain stable; stable resilient and non-resilient participants are characterised by continuing assets and resources. All those who change care status also change classification; all but one of these participants become resilient.

7.5 Discussion

Our first research objective was to examine spousal dementia carers' capacity to be resilient over time and across care status. The majority of carers remained either resilient or non-resilient. This is in line with previous research that found stable outcomes in spousal dementia carers over time (Gaugler et al., 2000; O'Connor & McCabe, 2011). Although one participant became non-resilient following the death of her spouse, the majority became resilient. Despite a gradual increase in stressors over time (Goldstein et al., 2006; Kramer, 2000), there are overall gains in resilience. This challenges the notion that caregiving is associated with impaired resilience to stress (Lavretsky et al., 2010; O'Connor & McCabe, 2011).

The patterns of resilience varied by care pathway. All continuing home carers remained either resilient or non-resilient; none became resilient. This contrasts with Kramer (2000), who found that wellbeing increases in dementia carers who continue to care at home. Most of our former carers remained or became resilient despite admitting their spouse into a care facility or becoming widowed; stable care status does not explain stable resilience over time. This supports the work of Schulz et al. (2003), who found that former carers may have a greater capacity to be resilient than continuing home carers. Institutionalisation and/or bereavement may remove or reduce the number of stressors, and elicit short- and long-term improvements in psychological health (Mausbach et al., 2007). Our findings support Bond et al. (2003), who found that spousal dementia carers who continued to provide care at home experienced stable quality of life. Overall, we suggest that these care status transitions are not always associated with negative physical and psychological effects (Bond et

al., 2003; Schulz et al., 1991). They differentially facilitate resilience, supporting the notion that resilience can increase over time (Gaugler et al., 2000).

Only those who were non-resilient at T1 admitted their spouse into a care facility. The anger and guilt experienced by these participants at T1 may have led them to institutionalise their spouse. This partially supports Gaugler et al. (2007), who found that low baseline resilience predicts care recipient death and institutionalisation. Although one of these former carers remained non-resilient, two became resilient. Institutionalisation of the care recipient may reduce the negative emotions experienced at T1, thus facilitating resilience at T2. This complements the work of Kramer (2000), who found that institutionalisation is associated with reduced stressors and stable wellbeing. These associations between resilience and institutionalisation preclude causality. Carer resilience is unlikely to cause care recipient death, but may protect against institutionalisation of the care recipient. The majority of our widowed former carers remained or became resilient over time. This supports Larkin's (2009) 'post-caring trajectory' through which widowed former carers gradually reconstruct their lives.

Our second research objective was to identify which assets and resources are associated with resilience and care status transitions. Stable resilient continuing home carers and widowed former carers were characterised by continuing individual assets, including: positivity; keeping the care recipient stimulated; and maintaining continuity pre- and post- care recipient death. On a community level, they continued to benefit from family support and the shared experience of group friends. This shows that the factors

identified in our previous work are carried through over time (Donnellan et al., 2015; Donnellan et al., 2016). It complements previous research which found that spousal carers experience stable mood and social support (O'Connor & McCabe, 2011). Stable resilient continuing home carers and widowed former carers differ in that the latter now have more time to pursue new leisure interests, such as holidaying alone and writing a book. Conversely, stable non-resilient continuing home carers and one former carer who institutionalised her spouse had continuing negative emotions, such as: resignation, anger and guilt. This supports Gaugler et al. (2000), who found that dementia carers report stable outcomes, such as depression, over time.

We found one participant who became non-resilient. This was unsurprising given that baseline psychological resilience is distinct from resilience outcomes (Bennett, 2015[b]; Spahni et al., 2015). The findings contradict O'Rourke et al. (2010), who found that being psychologically resilient at baseline was associated with reduced depressive symptoms at follow-up. After the death of her husband, Mrs Go. lost key individual assets, such as confidence, and community resources such as social participation. She also developed negative emotions, such as guilt. It is unclear whether the resources are no longer available or simply not being utilised. This supports previous findings that care status transitions are associated with negative physical and psychological effects (Bond et al., 2003; Goldstein et al., 2006; Kramer, 2000; Schulz et al., 1991), which impact quality of life and social support (Lavretsky et al., 2010; O'Connor & McCabe, 2011). It also supports Larkin's (2009) 'post-

caring void', where widowed former carers experience increased negative emotional experiences.

Finally, a large proportion of our former carers became resilient. As with stable resilient widowed carers, former carers who institutionalised their spouse reported more free time to return to previous resources, such as going to the gym and socialising with family. They also had more time to gain new resources, such as meeting new people and seeing a counsellor. This supports the notion that institutionalisation of the care recipient alleviates time constraints (Stephens et al., 1991) and provides functional relief of caregiving responsibilities (Bond et al., 2003). This leads to enhanced social support resources, fewer restrictions in social activities and greater satisfaction with social and leisure activities. Widowed former carers were characterised by reduced negative emotions. This complements Schulz et al. (2003) who found that widowed former carers experience significantly fewer depressive symptoms over time. Anticipatory grief may relieve some of the burden associated with caregiving (Garland et al., 2012; Holley & Mast, 2009; Schulz et al., 2006). Widowed former carers who became resilient were also characterised by gained individual assets such as acceptance and autonomy, and community resources such as a music hobby. Bennett (2010) found that these personal characteristics facilitate resilience in former caregiving widowers. Social activities have been associated with improved quality of life, mental health and perceived health status in former spousal dementia carers (Bond et al., 2003). These findings support Larkin (2009), who notes that widowed former carers gradually rebuild social relationships and pursue

leisure interests. Resources emerge from each level of the resilience framework (Windle & Bennett, 2011); care status transitions provide an opportunity to draw on more assets and resources over time.

The current study has a number of limitations. First, resilience and care status transitions may simply be driven by differences in care recipients' health status. Bond and Clark (2002) found that dementia severity was the best predictor of institutionalisation. Former carers may have been caring for spouses with substantially greater levels of impairment at T1, explaining their institutionalisation or death at T2 (Kramer, 2000). However, we found that care durations varied across groups, and all participants reported deteriorating health of the care recipient. Therefore, any confounding effect of care recipient health status is likely to be consistent across groups and unlikely to explain differences in resilience and care status transitions. Second, our small sample may limit comparisons of resilience across care status transitions. Compared to quantitative approaches, qualitative longitudinal research is less structured and it can be more difficult to retain a sample over time (Casey et al., 2011). However, we followed existing methods (Holland et al., 2006) and successfully re-interviewed more than half of the original sample, which requires great perseverance, networking and sensitivity. There is unlikely to be an extraneous reason driving drop out, as these participants were either deceased, untraceable or did not meet T2 inclusion criteria. Finally, we cannot assume directionality from our findings. For example, it is unclear whether resilient carers are more likely to remain caring at home, or whether continuing home

care provides stability to remain resilient over time. Further discussion of directionality goes beyond the scope of this study.

In conclusion, we found that carers can remain or become resilient over time despite deteriorating health, institutionalisation, and death of the care recipient. Institutionalisation and widowhood are not always barriers to resilience; indeed, they differentially facilitate resilience. This is important as studies rarely distinguish between different types of former carer. Stable resilience was characterised by continuing assets and resources. Former carers gained a range of resources from each level of the framework, suggesting that care status transitions provide an opportunity to draw on more assets and resources over time.

PART FOUR

DISCUSSION AND CONCLUSIONS

Chapter 8

Providing informal care: How to facilitate resilience in challenging times: Synthesis of research findings

8.1 Introduction

This thesis set out to use Windle and Bennett's (2011) ecological framework to identify and explore resilience in informal carers. We asked three research questions: first, can older informal carers achieve resilience? Second, what are the individual assets, community and societal resources that facilitate or hinder resilience in older informal carers? Third, what are some of the mechanisms through which individual assets, community and societal resources facilitate or hinder resilience in informal carers over time? To address research questions 1 and 2, Chapter 3 classified older spousal dementia carers as resilient or not, identified the factors associated with resilience, and examined whether they could be mapped on to the resilience framework (Windle & Bennett, 2011). Chapter 4 considered the predictive relationships between individual assets, community and societal resources and resilience in a non-spousal carer sample. To address research question 3, Chapter 5 used quantitative methods to explore the age-related positivity effect in carers and non-carers across the life course. Chapters 6 and 7 extended and further explored data utilised in Chapter 3. Chapter 6 explored the availability, function and perceived functional aspects of support and resilience in older spousal dementia carers. Using qualitative longitudinal follow-up data, Chapter 7 examined changes in resilience, assets and resources through care status transitions in older spousal dementia carers

over time. This Chapter discusses the main findings of the thesis in view of these research questions, integrating previous research.

8.2 Overview and theoretical implications of findings

8.2.1 Research question 1: Can older informal carers achieve resilience?

Using qualitative and quantitative methods, Chapter 3 found that 8/20 older spousal dementia carers achieved resilience and Chapter 4 found that 418/646 older informal carers achieved resilience. Our findings suggest that both spousal and non-spousal caregiving is not entirely burdensome, contrary to previous research (Bertrand et al., 2006; Etters et al., 2008; Pinquart & Sörensen, 2003[b]); some carers can achieve resilience. These findings support the notion that carers are a heterogeneous group (Bertrand et al., 2006; Pickard, 2004; Rutter, 2012); there are individual differences in response to stressors. This suggests that the exclusive study of caregiver burden may be insufficient; Chapters 3 and 4 show that positive states coexist with negative states throughout caregiving (Folkman, 1997). By focusing on burden and taking a burden-centric approach to the study of resilience (Cherry et al., 2013), researchers overlook positive experiences. Resilience captures the complex interplay between burden and wellbeing (Ungar, 2012).

Our findings support the person focused approach to resilience measurement; that is, classifying groups of individuals who show similar patterns of resilience in order to characterise contributing factors (Masten, 2001). We were previously unaware of any resilience measurement criteria

specific to carers. Based on two studies of resilient widowers (Bennett, 2010; Moore & Stratton, 2003) and Windle's (2011) resilience definition, Chapter 3 classified resilient carers using the following criteria: i. There must be a significant challenge: caregiving; ii. No sign of distress; iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back); iv. Actively participating in life (a sign of managing); v. Current life seen as positive (a sign of adaptation). Chapter 4 classified resilient individuals using a standard proxy method of high life satisfaction (Chappell & Dujela, 2008) and no depression (Galatzer-Levy & Bonanno, 2012; Hardy et al., 2004) in the face of caregiving (adversity). We established resilience classifications that were approximately in line with resilience prevalence rates from four longitudinal studies on family dementia carers (Joling et al., 2015[b]). This suggests that both qualitative and quantitative measurement methods are appropriate for carers.

8.2.2 Research question 2: What are the individual assets, community and societal resources that facilitate or hinder resilience in older informal carers? Windle and Bennett's (2011) ecological resilience framework was theoretical and had not been tested empirically on informal carers. In Figure 8.1 we present a refined framework which operationalises resilience and illustrates some of the key findings from the thesis. Chapters 3 and 4 identified a number of assets and resources which emerged on mainly individual, but also community and societal levels, for example: maintaining continuity; staying positive; acquisition of knowledge; and friendships with common experience. We found interactions between individual assets, community and societal resources. For example, Chapter 3 found that striving to acquire expertise (individual assets) drew some

carers to seek out information and go to a carer support group (societal resource). By attending support groups, carers shared information and provided social support to one another (community resource). In Chapter 4 we found that psychologically resilient carers, and those with three or more friends available for practical support were more likely to be resilient. We also found that hindering factors emerged on individual, community and societal levels. Chapter 3 found that a resigned outlook, over-involved family support, disengagement from existing friends and social isolation all hindered resilience. Chapter 4 found that carers who use more services were less likely to be resilient. These findings demonstrate that Windle and Bennett's (2011) framework can be applied to older spousal dementia carers and non-spousal informal carers; resilience is an ecological and interactive construct (Bonanno et al., 2007; Ungar, 2011; Windle, 2011); resilience factors interact with interpersonal and socio-environmental factors (Bennett & Windle, 2015; Liebenberg & Ungar, 2009; Luthar, 2006; Ungar, 2015).

Although the same theoretical framework was used in each Chapter, not all findings from Chapter 3 were replicated in Chapter 4, for example: gender; age; social class; frequency of family and friends; and attendance at social groups. Furthermore, Chapter 4 found that service use was associated with non-resilience whereas Chapter 3 found that some services, such as respite care, facilitated resilience. Although this is likely to reflect differences in research method, sample size and analysis, it poses some theoretical implications. These findings could suggest that there are differences in resilience between spousal dementia carers and non-spousal informal carers. Indeed, studies have shown

that there are differences between dementia and non-dementia carers and spousal and non-spousal carers in terms of burden, depression (Bertrand et al., 2006; Pinquart & Sorensen, 2003[b]) and physical health (Pinquart & Sörensen, 2007). Only the most consistent findings from across the thesis were included in Figure 8.1. The refined framework is by no means exhaustive; different factors matter more than others at different times and in different contexts (Bennett, 2010; Ungar, 2015); resources do not protect all people all of the time (Iparraguirre, 2015).

A key finding to emerge from Chapter 3 was that some resources are only facilitating up until a point, after which they become hindering, for example: disposable income; family support; and respite care. This suggests that carers do not simply draw on individual assets, community and societal resources which facilitate or hinder resilience (Windle & Bennett, 2011); access to resources from across the resilience framework is not always sufficient; resources must match perceived need and carers must wish to use them. Chapter 3 also found that some resilient carers drew on hindering factors and some non-resilient carers drew on facilitating factors. This suggests that resilience may not be a clear cut binary outcome, contrary to what we have proposed throughout the thesis. This is consistent with Spahni et al. (2015), who identified a middle group of bereaved individuals, called 'copers', who do not meet all resilience criteria, but are not non-resilient. However, there is a lack of clarity on how the 'copers' group should be conceptualised, and indeed whether it is even relevant in carers. Kalisch et al. (2015) argue that resilience is best understood as a continuous quantitative outcome variable. However,

Southwick et al. (2015) argue that complex adaptive systems rarely change in a linear manner. Although Windle and Bennett's (2011) framework can be applied to older informal carers, the resilience process may be more complex than first thought. The applied implications of these findings will be discussed later.

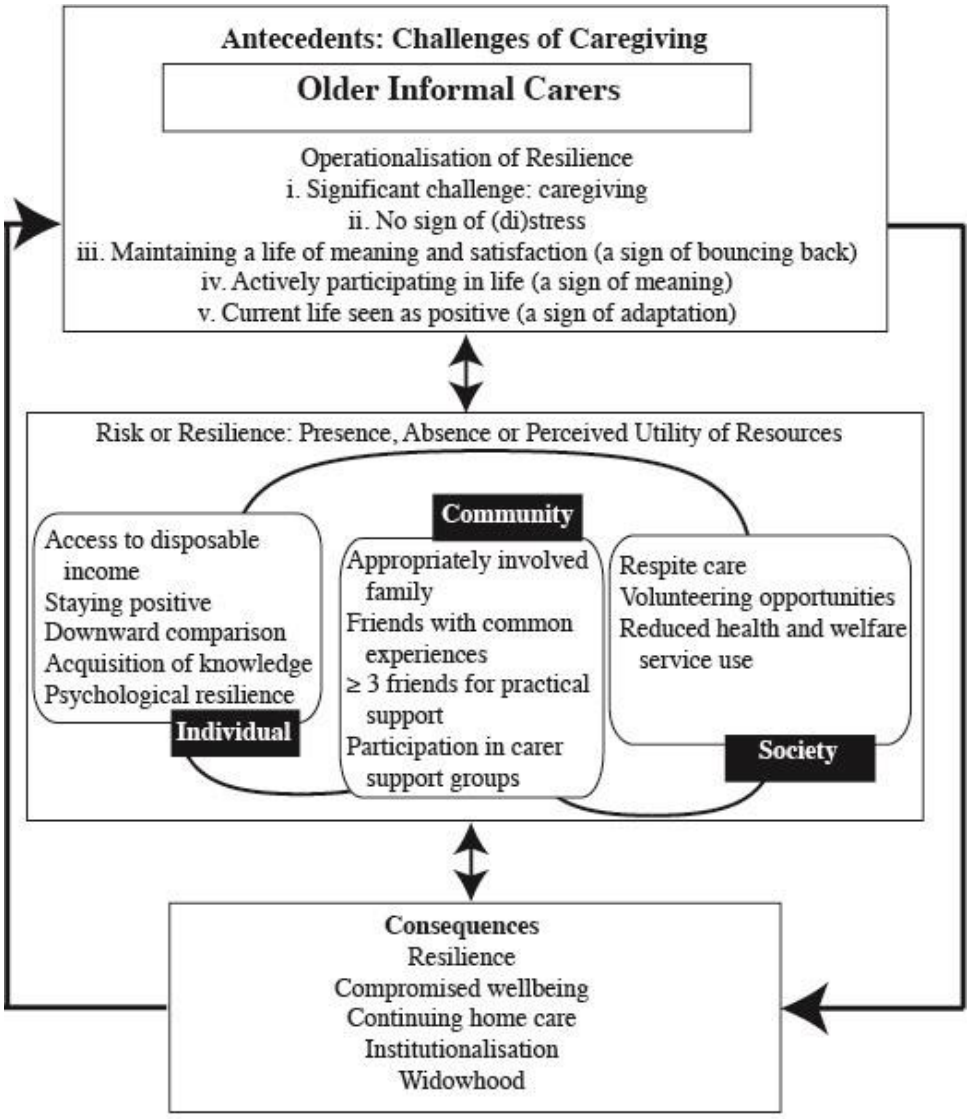

Figure 8.1: Refined ecological resilience framework, based on the key findings from the thesis.

8.2.3 Research question 3: What are the mechanisms through which individual assets, community and societal resources facilitate or hinder resilience in informal carers over time?

Chapter 5 found that carers and non-carers displayed an emotional enhancement effect across the life course. However, older people were unique in that they displayed a positivity bias, with some evidence to suggest that this was more pronounced in older carers than older non-carers. Importantly, the findings were independent of education level and current mood. This contrasts with previous research which found that carers are more likely than non-carers to experience stress, depressive symptoms (Joling et al., 2010; Pinquart & Sörensen, 2003[b]; Shah & Wadoo, 2010), lower levels of subjective wellbeing and self-efficacy (Pinquart & Sörensen, 2003[b]). The findings suggest that positive psychological states may be separate from but coexist with negative psychological states, such as burden, in carers (Boerner et al., 2004; Folkman, 2008). Focusing exclusively on burden overlooks these important positive experiences. Positive states are important because they can help to sustain the motivation to provide care (Folkman, 1997).

Our findings suggest that there is something specific about older carers that explains their increased positivity. The carers could be drawing on individual-level resilience resources, including satisfaction, enjoyment, closeness (Pinquart & Sörensen, 2003[a]), optimism, self-esteem (Zauszniewski et al., 2009), insight, acceptance, humour (Cheng et al., 2016), and benefit finding (Folkman, 2008; Roth et al., 2015). Increased positivity in older carers may mediate the relationship between caregiver burden and resilience (Bekhet,

2013; Carbonneau et al., 2010). This complements the notion that positivity is an individual asset that carers draw on to facilitate resilience (Windle & Bennett, 2011). According to PASTOR theory, the older carers may positively appraise their caregiving circumstances more effectively (Kalisch et al., 2015). Socioemotional selectivity theory predicts that older carers may be demonstrating a positivity bias as knowledge and future-oriented goals give way to emotional gratification and present-oriented goals as they transition into late adulthood (Carstensen, 2006; Reed et al., 2014). This suggests that older carers should be more resilient. This contrasts with Chapter 3, which found that older carers were less likely to be resilient than younger carers. Unfortunately, Chapter 5 did not include a specific measure of resilience; although one would expect resilient carers to elicit a significantly higher positivity bias (Bennett, 2010; Carstensen & Fredrickson, 1998; Carstensen & Mikels, 2005; Donnellan et al., 2015), we cannot be sure without testing it explicitly. Furthermore, the notion of a single individual-level resilience mechanism may be too reductionist (Kalisch et al., 2015; Ungar, 2015).

Another key finding from Chapter 3 was that resilient carers were well-supported by family but especially friends, with whom they shared this knowledge. Contrary to previous literature, Chapter 6 found that resilient and non-resilient carers had structurally and functionally similar support characteristics (Cheng et al., 2016; Ellwardt et al., 2013; Gaugler et al., 2007; Han et al., 2014; Milne et al., 2007; Morbey, 2015; Ross et al. 2003; Walsh, 2012). Resilient carers were no more likely to have family and friend support available to them, and they served similar functions for resilient and non-

resilient carers. It was unclear whether the structure or function of support best captured resilience in carers (Roth et al., 2005). In line with Chapter 3, this suggests that social networks and social support are not always sufficient to facilitate resilience. This is consistent with the notion that the mere presence/absence of resources, such as close social ties, does not simply facilitate carer resilience (Sherman et al., 2013; Thetford et al., 2015).

Chapter 6 found that family and friend support facilitates resilience through the following mechanisms. Whilst most carers preferred 'intimacy at a distance' regarding family support (Erkert, 1992; Rosenmayr, 1983; Ingersoll-Dayton et al., 1997; Pinquart & Sörensen, 2000), non-resilient carers actively resisted over-involvement and justified it in terms of their competing demands. Research shows that support may be detrimental if it creates feelings of over-dependence (Ingersoll-Dayton et al., 1997) or if it is not empathic (Haley et al., 1987). As discussed in Chapter 3, this suggests that some support resources are only facilitating up until a point, after which they become hindering (Donnellan et al., 2015). An abundance of support resources could indicate resilience, but it could indicate non-resilience if the resources do not match current need.

The perceived function of friends was different from the perceived function of family. We found that resilient carers were more likely to receive support from friends with shared experience, whereas friends of non-resilient carers served a narrower function. Shared experience may explain why resilient carers gained support group friends; they had more in common (Arskey et al., 2002; Farran et al., 2004; Han et al., 2014; Harris, 2013; Sörensen et al., 2006). It may also explain why existing friends were more likely to disengage from non-resilient carers; they had little in common anymore (Clay et al., 2008; Han

et al., 2014; Hough et al., 2005). Taken together, these findings suggest that the association between support and resilience is moderated not by structural or functional support characteristics, but the perception of that support (Deist & Greeff, 2015; Ellwardt et al., 2013; Luthar, 2006; O'Rourke & Tuokko, 2000; Roth et al., 2005; Sherman et al., 2013; Wilks & Croom, 2008). However, the previous findings were cross-sectional and the resilience framework had not yet been tested longitudinally. These assets and resources are known to vary over time and through care status transitions (Gaugler et al., 2007; Ross et al., 2003). These transitions represent mechanisms through which assets and resources facilitate resilience.

Using qualitative longitudinal follow-up data, Chapter 7 found that, despite an increase in stressors (Goldstein et al., 2006; Kramer, 2000), the majority of older spousal dementia carers remained or became resilient; there were overall gains in resilience over time. These findings suggest that resilience is not simply a fixed trait (Bonanno et al., 2007; Windle et al., 2010), but a dynamic developmental process through which a resilient outcome unfolds in response to stressors over time (Bennett, 2015[b]; Bonanno & Diminich, 2013; Joling et al., 2015[a]; Kalisch et al., 2015; Luthar, 2006; Windle et al., 2008; Windle et al., 2010).

We found that continuing home carers remained either resilient or non-resilient over time. However, a large proportion of former carers remained or even became resilient despite admitting their spouse into a care facility or becoming widowed. Specifically, we found evidence to suggest that institutionalisation of the care recipient may reduce the negative emotions experienced at T1, thus facilitating resilience at T2 (Kramer, 2000). Widowed

former carers may experience anticipatory grief which reduces caregiver burden (Garland et al., 2012; Holley & Mast, 2009; Schulz et al., 2006), and gradually reconstruct their lives following the loss of their spouse (Larkin, 2009). According to Rutter (2012), the stresses of caregiving and/or institutionalisation may protect against widowhood through a steeling effect. It is unclear from the data whether the care status transition was the turning point after which the carers became resilient, or whether it was a more gradual process (Bennett, 2010; Mancini & Bonanno, 2009). However, the fact that transitioning carers were more likely to change resilience status suggests that the former is true. Contrary to the notion that institutionalisation and widowhood are associated with negative physical and psychological effects (Bond et al., 2003; Schulz et al., 1991), this suggests that care status transitions differentially facilitate resilience over time (Bond et al., 2003; Gaugler et al., 2000; Schulz et al., 2003).

Finally, we found that stable resilient continuing home carers and widowed former carers were characterised by continuing individual assets and community resources (O'Connor & McCabe, 2011). These included many of the resilience factors highlighted in our previous work (see Donnellan et al., 2015; Donnellan et al., 2016), suggesting that assets and resources are stable rather than fluctuating (Windle et al., 2010). Conversely, stable non-resilient continuing home carers and one former carer who institutionalised her spouse were characterised by continuing negative emotions (Gaugler et al., 2000). Unlike continuing home carers, both groups of former carers reported more free time to return to previous resources, such as going the gym, and gain new resources, such as seeing a counsellor. This suggests that functional relief of

caregiving responsibilities and subsequent free time are important mechanisms through which resilience resources are returned to or gained following a care status transition (Bond et al., 2003; Stephens et al., 1991). In line with Chapters 3 and 4, resources emerge from each level of the resilience framework (Windle & Bennett, 2011), suggesting that care status transitions provide an opportunity to draw on more assets and resources over time. The findings confirm that the developmental trajectory of resilience is as important to consider as its component parts.

8.3 Recommendations

8.3.1 Practitioners and policy makers

The findings of this thesis have a number of applications for those involved in the design of support services for informal carers.

8.3.1.1 Recommendation 1

First, practitioners and policy makers should take an ecological approach when working with carers. The informal and formal support literature is predicated on the assumption that all carers are burdened and vulnerable. This is not always the case; by operationalising resilience using Bennett's (2010) criteria, we were able to identify resilient and non-resilient carers. This allows support services to be appropriately targeted towards those most in need and learn from resilient carers in order to help the former (Fergus & Zimmerman, 2005). If we can identify the dynamic interplay between assets and resources that carers draw on to facilitate resilience then practitioners and policy makers can

design socio-environmental support services to promote them in carers (Windle, 2011).

For example, research shows that carers can find it difficult to acknowledge emotional aspects of their role (Milligan & Morbey, 2013), and practitioners tend to focus on practical over emotional support needs (Morbey, 2015). We found age differences in emotional processing between young, middle-aged and old carers and non-carers. Specifically, there was evidence to suggest that older informal carers elicit a positivity bias. Practitioners should acknowledge that carer emotional support needs vary over the life course; younger carers may be more at risk than older carers. Resilient carers are more likely to acquire information and expertise on dementia and wish to share it with other carers. Services should ensure that information is easily accessible and provide forums within which the acquisition and provision of support is possible.

8.3.1.2 Recommendation 2

Second, support services should be accessible for all, but intervention is only necessary for the minority when burden is too high. There are examples throughout this thesis where support resources only facilitate resilience if they match perceived need. For example, family support that is perceived as over-intensive may create feelings of dependence. Some carers feel that they are not ready for respite care or are unaware of its availability (Brodaty et al., 2005; Philipson et al., 2010). Access to resources is not always sufficient to facilitate resilience; there may be a gap between actual and perceived need for support.

Practical attempts to reduce loneliness or increase number of support services may be futile; it is not the number of services that is important for resilience in carers. Social policy and carer assessments should not just consider the objective level of carer stressors (Pickard, 2004; Seddon et al., 2006), but also their perceived satisfaction with support (Deist & Greeff, 2015; Luthar, 2006; O'Rourke & Tuokko, 2000; Roth et al., 2005; Sherman et al., 2013; Thetford et al., 2015).

8.3.1.3 Recommendation 3

Third, interventions should consider the heterogeneity of carers and be personalised and tailored to the actual and perceived needs of carers (Bennett, 2015[a]; Kalisch et al., 2015; Pinquart & Sörensen, 2006; Sörensen et al., 2002). Sörensen et al. (2002) found that interventions were less effective for spousal dementia carers. This is important because this thesis focused largely on this group. Carer support services are practical and problem-focused, and do not routinely assess the rewarding aspects of caregiving (Seddon & Robinson, 2015). By understanding these aspects and aiming to facilitate resilience as well as alleviate disorder (Liebenberg & Ungar, 2009), carer interventions may be more efficacious.

As previously discussed, Chapter 4 found that increased service use predicts non-resilience in older informal carers. This reminds us that there is no 'one-size-fits-all' solution for carer support services (Bennett, 2015[a]). For example, non-resilient carers may be more at risk of isolating themselves from family members which may be particularly damaging if they have fewer

alternative individual and societal resources (Windle & Bennett, 2011). Non-resilient carers may be more likely to admit their spouse into a care facility and wait later in the disease process before using formal services (Bookwala et al., 2004). This suggests that support services do not protect all people all of the time (Iparraguirre, 2015). Support services matter more than others at different times and in different contexts (Bennett, 2010; Milligan & Morbey, 2013; Ungar, 2015).

8.3.2 Informal carers

Our research was not originally intended to provide recommendations to carers. However, our findings have a number of important practical applications for carers.

8.3.2.1 Recommendation 1

First, it is important to note that caregiving is not entirely burdensome and resilience is not fixed; non-resilient carers can become resilient over time despite deteriorating care recipient health and care status transitions. In the event of a care status transition, such as institutionalisation or widowhood, the carer may benefit from relieved time constraints by returning to old or gaining novel leisure pursuits.

8.3.2.2 Recommendation 2

Second, carers may benefit from drawing on their own individual assets, but also their community and societal resources to facilitate their capacity for resilience. On an individual level, resilient carers can stay positive, maintain

continuity and acquire knowledge on dementia. On a community level, resilient carers can be supported by appropriately involved family members that foster independence. For emotional support, resilient carers can surround themselves with like-minded friends with shared interests. For practical support, they may call on as many friends as possible. An ideal forum to foster both of these is a club, church group or support group setting where expertise and experience can be acquired and shared. On a societal level, resilient carers may seek out and accept formal support services such as respite care, but only on their own terms as not to relinquish their feelings of independence and autonomy.

8.4 Outstanding issues and future directions

The findings of this thesis highlight a number of outstanding issues and possible directions for future research. Using an ecological approach to resilience, we successfully identified a number of previous unexplored assets and resources in informal carers. This supports the continued need to examine resilience from an ecological perspective. Windle and Bennett's (2011) framework was theoretical so the assets and resources were not exhaustive and neither necessary nor sufficient for resilience. However, there were some outstanding resources, such as biological assets, ethnicity, housing factors, and social policy. Societal resources did not emerge as much as community and individual assets in our qualitative work. This may reflect our methodological approach, which largely captured the affective and behavioural reactions to caregiving. For example, Wild et al. (2011) found that societal resources emerge when participants are asked about them. Future research should attempt to capture outstanding and novel resources using different methods of research and analysis.

Our multi-method approach is a significant strength (Happ, 2009). Our in-depth qualitative methodology captures complex resilience processes, informing future qualitative and quantitative work to draw out the theoretical and practical implications of this thesis (Rutter, 2012). We classified individuals as resilient or not in order to characterise emergent resilience resources. The criteria used have been used in other studies on resilience (Bennett et al., 2016; Thetford et al., 2015), thus providing validation. Some would argue that deductive classification is at odds with the inductive open-ended principles of constructivist grounded theory (Charmaz, 2014). However, we do not claim that our methods are traditional; we adapted them to fit our research questions (Chamberlain, 2012). Our binary resilience classification may be overly simplistic given the overall approach of the thesis is rich and complex. Throughout the thesis we acknowledge the possibility of a 'middle group' of carers who are neither resilient nor not resilient. Future research could use more sophisticated quantitative analysis to investigate the conceptual structure of resilience. For example, we could use the latent profile analysis seen in Spahni et al. (2015) to identify patterns of resilience in carers, using the emergent assets and resources as dependent variables.

Comparison within and between our exploratory Chapters was limited by differences in research method and sample size. Researchers have argued that grounded theory studies should include between 30 and 50 interviews (Denzin & Lincoln, 2005), whereas our qualitative samples included between 13 and 23. This limits the credibility of the research, which makes the findings less rigorous (Houghton et al., 2012). However, our sample size was determined by

theoretical sampling; we stopped interviewing when theme saturation was reached (Charmaz, 2014). In all Chapters this fell above the saturation threshold of 12 interviews set by Guest et al. (2006). Future research should draw on alternative methodological frameworks, such as phenomenology and ethnography, to examine whether the findings are transferable (Lincoln & Guba, 1985).

Throughout the thesis we sampled a variety of carers, from spousal dementia carers in Chapters 3, 6 and 7, to older informal carers in Chapter 4 and young, middle-aged and old carers and non-carers in Chapter 5. In our qualitative work there was a mix of current and former spousal dementia carers. Research shows that the experience of caregiving between current and former carers (Schulz et al., 2003) and dementia and non-dementia carers (Bertrand et al., 2006) is quite different. This limits the dependability of the findings (Graneheim & Lundman, 2004; Lincoln & Guba, 1985). Future investigations could increase dependability by isolating and analysing carers with certain characteristics, for example; current spousal dementia carers over the age of 65. However, our former carers had a wealth of experience that they wanted to share. Excluding individuals on the grounds of dependability would go against the inductive, participant-led principles of qualitative research.

Our qualitative work sampled participants who cared for people with a range of dementia types, including Alzheimer's disease and vascular dementia. Chapter 5 sampled carers of people with a range of physical and mental health issues including dementia, but also cancer and learning difficulties. The care recipients were all at different disease stages. We had access to some of this

information, such as care intensity in Chapter 5 and the fact that all participants reported that their spouse's health had deteriorated in Chapter 7, but we did not control for it in our analyses. This is a problem because research has shown that frequency and severity of care recipient problems negatively influences carer resilience (Cherry et al., 2013). However it should be noted that not all care recipients have a diagnosis and not all carers have access to the care recipient's health status information (Schindler et al., 2012). Future studies should collect as much care recipient health status information as possible and control for it in qualitative and quantitative analyses. Our qualitative Chapters sampled carers mostly from support groups (17/23). This has implications for resilience; resilient carers may be more likely to attend support groups, creating a resilient sub-group of carers (Arskey et al., 2002; Han et al., 2014). This means that the findings cannot be transferred to carers who do not attend support groups (Lincoln & Guba, 1985). However, it is worth mentioning that not all participants were recruited from support groups and not all those participants recruited from support groups are resilient. Furthermore, it is difficult to recruit those carers who are not known to services. Future research should look to recruit a more representative sample of carers from different sources.

We established a number of findings in Chapter 3 that were not replicated in Chapter 4, suggesting that there are differences between spousal dementia carers and non-spousal carers. However, Chapter 3 used qualitative interview data and Chapter 4 used secondary data in the form of CFAS Wales. CFAS Wales was not originally designed with caregiver resilience in mind

(Tripathy, 2013), so we did not have appropriate measures of caregiver adversity or resilience. We had to assume that caregiving was an adversity for most people, and used a resilience proxy of high life satisfaction and no depression. Being a carer does not necessarily equate to adversity, and having high life satisfaction and no depression does not necessarily indicate that the individual is resilient. These outcomes overlook the characteristics and processes that contribute to resilience (Windle et al., 2010). However, there is no 'gold standard' measure of resilience (Windle et al., 2011). Proxy operationalising resilience is commonly used in the caregiving literature (Gaugler et al., 2007; Joling et al., 2015[b]). Future research should verify the findings using a more representative sample of carers and more specific measure of resilience.

A significant strength of Chapter 7 was its qualitative longitudinal approach (Calman et al., 2013). It would be interesting to examine how far the qualitative longitudinal findings extend to quantitative longitudinal work. Future research could use CFAS Wales Wave 2 data to follow Chapter 4 carers through transitions within caregiving and into other late life challenges. From this we would gain a more comprehensive insight into the ongoing development of resilience. Throughout the thesis there was a focus on older spousal dementia carers. This was because spousal dementia care was shown to be uniquely stressful (Etters et al., 2008; Pinquart & Sörensen, 2003[a]). It would be interesting to examine how the assets and resources of these carers compare with those of other carers of different ages and care recipient problems. This is important because carers face age-specific challenges, for example; middle-aged

carers may be more likely to be caring for multiple people across multiple generations (Grundy & Henretta, 2006; Windle & Bennett, 2011). Chapter 5 examined young and middle-aged carers of people across a range of relationships and diagnoses. However, future research with an increased sample size and more specified sample of carers is needed to examine the precise point at which a positivity effect originates, and whether it holds through care status transitions.

Our findings reveal a number of interpersonal factors that facilitate resilience. However, these factors were largely based on the carer's experiences; we did not interview care recipients or other carers. Spousal carers are often not the only primary carer. Future research should study care dyads (e.g. wife carer and husband care recipient) and carer dyads (e.g. wife-daughter caring for father). Although the former may be methodologically challenging in mid- to late-stage dementia due to the cognitive demands of an interview, it may uncover hidden aspects of the reciprocal nature of the relationship and reduce carer bias (Braun et al., 2010).

Throughout the thesis we have assumed a uni-directional association between resources and resilience, whereby carers draw on individual assets, community and societal resources which facilitate or hinder resilience (Windle & Bennett, 2011). However, there are examples in our data where the opposite is true. In Chapter 4 it was unclear whether increased service use was driving non-resilience, or whether non-resilient carers were more likely to use more services. In Chapter 6 there were examples where the social interactions of resilient carers were targeted towards particular support functions. In Chapter

7 it was unclear whether resilient carers were more likely to remain caring at home or whether continuing home care provides stability to remain resilient over time. That said, the resilience framework does posit that resources facilitate resilience when then feeds back to create further challenges and resources (Windle & Bennett, 2011). More research is needed to explore these complex associations. Further discussion of directionality goes beyond the research objectives of this thesis.

8.5 Conclusion

This thesis aimed to identify and explore resilience in informal carers using Windle and Bennett's (2011) ecological framework. We qualitatively and quantitatively validated and explored the framework in different carers of different ages, both cross-sectionally and longitudinally. This thesis makes an important contribution to the literature and has implications for future research, policy, practice and carers themselves. The following conclusions can be drawn from the findings. First, informal caregiving is not entirely burdensome; despite the stress of caregiving, carers draw on a range of individual assets, community and societal resources to facilitate their capacity for resilience. Second, resilience transcends the individual; the findings emphasise the importance of social ecological approaches whereby resources interact to facilitate or hinder resilience. Third, the mechanisms through which resources facilitate resilience are not always straightforward; some resources facilitate resilience up until a point after which they become hindering. Practitioners and policy makers should deliver personalised support services that match the carer's actual and perceived need.

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Appendix 1

Ethics form and approval email: Qualitative studies

UNIVERSITY OF LIVERPOOL

Office Use Only
Reference Number:
Date Received:

COMMITTEE ON RESEARCH ETHICS

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING

HUMAN PARTICIPANTS, HUMAN DATA, OR HUMAN MATERIAL

This application form is to be used by researchers seeking approval from the University Committee on Research Ethics or from an approved School Research Ethics Committee.

Applications to the University Research Ethics Sub-Committees, with the specified attachments, should be emailed to ethics@liv.ac.uk. Applications to an approved School Committee should be submitted to their local address, available at http://www.liv.ac.uk/researchethics/deptcommittees.htm.

This form must be completed by following the guidance notes, accessible at www.liv.ac.uk/researchethics. Incomplete forms will be returned to the applicant.

SECTION A - IDENTIFYING INFORMATION

A1) Title of the research

The development of resilience over time among caregivers of relatives with dementia: variations and mediations within and between spousal and parental relationships.

A2) Principal Investigator ☐ OR Supervisor ☒ (please check as appropriate)

Title:	Dr	**Staff number:**	
Forename/Initials:	K M	**Surname:**	Bennett
Post:	Senior Lecturer	**Department:**	Psychology
Telephone:	0151 794 1410	**E-mail:**	kmb@liv.ac.uk

A3) Co-applicants *(including student investigators)*

Title and Name	**Post**	**Department/ School/Institution if not UoL**	**Phone**	**Email**
Warren Donnellan-Smith	Undergraduate		07716405098	ps0u9265@student.liverpool.ac.uk
Jessica Butler	Undergraduate		07532177711	ps0u9276@student.liverpool.ac.uk

Declaration of the:

Principal Investigator ☐ OR Supervisor and Student Investigator ☒
(please check as appropriate)

- The information in this form is accurate to the best of my knowledge and belief, and I take full responsibility for it.

- I undertake to abide by the ethical principles underlying the Declaration of Helsinki and the University's good practice guidelines on the proper conduct of research, together with the codes of practice laid down by any relevant professional or learned society.

- If the research is approved, I undertake to adhere to the study plan, the terms of the full application of which the REC has given a favourable opinion, and any conditions set out by the REC in giving its favourable opinion.

- I undertake to seek an ethical opinion from the REC before implementing substantial amendments to the study plan or to the terms of the full application of which the REC has given a favourable opinion.

- I understand that I am responsible for monitoring the research at all times.

- If there are any serious adverse events, I understand that I am responsible for immediately stopping the research and alerting the Research Ethics Committee within 24 hours of the occurrence, via ethics@liv.ac.uk.

- I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.

- I understand that research records/data may be subject to inspection for audit purposes if required in future.

- I understand that personal data about me as a researcher in this application will be held by the University and that this will be managed according to the principles established in the Data Protection Act.

- I understand that the information contained in this application, any supporting documentation and all correspondence with the Research Ethics Committee relating to the application, will be subject to the provisions of the Freedom of Information Acts. The information may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

- I understand that all conditions apply to any co-applicants and researchers involved in the study, and that it is my responsibility to ensure that they abide by them.

- For Supervisors: I understand my responsibilities as supervisor, and will ensure, to the best of my abilities, that the student investigator abides by the University's research ethics code at all times.

- For the Student Investigator: I understand my responsibilities to work within a set of safety, ethical and other guidelines as agreed in advance with my supervisor and understand that I must comply with the University's regulations and any other applicable code of ethics at all times.

Signature of Principal Investigator ☐ **or** **Supervisor** ☒**:**
.....

Date: (13/05/11)

Print Name: Kate M Bennett

Signature of Student Investigator: .....

Date: (13/05/11)

Print Name:

SECTION B - PROJECT DETAILS

B1) Proposed study dates and duration

Start date:	01/07/11	**End date**:	01/09/11

B2) Give a full summary of the purpose, design and methodology of the planned research.

This study will examine the experience of caring for a spouse or parent with dementia; particularly the development of resilience and how this varies by relationship type. The negative consequences of caregiving such as emotional, physical, social and financial burden (Morris, 1998) have left caregivers as the 'hidden victims' (Haley, 1987). However, less understood within this arena is how caregivers become sufficiently resilient to cope with the unique stress (Ory et al., 1999) of 'long bereavement' or dementia. Furthermore, there is more to be understood about the precise challenges within and between the caregiving of spouses and offspring, especially with regard to dementia care. For instance, changes to the balance of spousal relationships have been observed (Quinn et al., 2008) whereas a subtly different form of inequity has been noted among the offspring siblings, particularly in the division of labour (Dayton et al., 2003). Positive aspects of caring such as pride, family solidarity and social support take less presedence despite being key to the dyadic outcomes of both caregiver and care recipient and the development of resilience in the caregiver. With the number of new dementia cases projected to treble by 2050 (Herbert et al., 2001) there is an urgent and iminent need for an increased understanding of the positives of caregiving (resilience) away from the more popular detriments. Understanding and publisicing this cause may also go some way to lessening the burden felt on informal and formal care (e.g. care homes), keeping care-recipients at home in familiar and comfortable settings for longer with as little impact on the caregiver as possible. There is a great deal to be learnt through in-depth qualitative studies which explore the subjective and lived experience of informal caregiving. This study aims to investigate the development of resilience over time of those in active care of spouses or parents with dementia.

The design will be a qualitative interview study. Participants will be interviewed in depth about their experiences of caregiving, in particular changes in

relationships and development of resilience over time in a progressive overview starting from the time of their relative's dementia diagnosis through to the time of interview. Examples of typical interview schedules are attached. The numbers of participants interviewed will be at least 15. Particpants will be recruited from local caregiver support groups and from from dementia cafes provided for caregivers. Data will be analysed using grounded theory based on the method used by Bennett and Vidal-Hall (2000). Whilst answers to the specific research questions can be obtained in this way, the advantage of this technique is that theory development can take place.

B3) List any research assistants, sub-contractors or other staff not named above who will be involved in the research and detail their involvement.

None

B4) List below all research sites, and their Lead Investigators, to be included in this study.

Research Site	**Individual Responsible**	**Position and contact details**
University of Liverpool	Kate M Bennett	Senior Lecturer ext 41410
Places as yet unknown	Kate M Bennett	Senior Lecturer ext 41410

B5) Are the results of the study to be disseminated in the public domain?

YES ☒ NO ☐

- ***If not, why not?***

B6) Give details of the funding of the research, including funding organisation(s), amount applied for or secured, duration, and UOL reference

Funding Body	Amount	Duration	UoL Reference
None			

B7) Give details of any interests, commercial or otherwise, you or your co-applicants have in the funding body.

None

a) Will the study involve recruitment of participants outside the UK?	No
b) Does the study involve participants who are particularly vulnerable or unable to give informed consent? *(e.g. children, people with learning or communication disabilities, people in custody, people engaged in illegal activities such as drug-taking, your own students in an educational capacity) (Note: this does not include secondary data authorised for release by the data collector for research purposes.)*	No
c) Will the study require obtaining consent from a "research participant advocate" (for definition see guidance notes) in lieu of participants who are unable to give informed consent? *(e.g. for research involving children or, people with learning or communication disabilities)*	No
d) Will it be necessary for participants, whose consent to participate in the study will be required, to take part without their knowledge at the time? *(e.g. covert observation using photography or video recording)*	No
e) Does the study involve deliberately misleading the participants?	No
f) Will the study require discussion of sensitive topics that may cause distress or embarrassment to the participant or potential risk of disclosure to the researcher of criminal activity or child protection issues? *(e.g. sexual activity, criminal activity)*	Yes
g) Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No
h) Will samples (e.g. blood, DNA, tissue) be obtained from participants?	No
i) Is pain or more than mild discomfort likely to result from the study?	No

j) Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	No
k) Will the study involve prolonged or repetitive testing?	No
l) Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	No

SECTION C - EXPEDITED REVIEW

C1)

C2)

a) Will the study seek written, informed consent?	Yes
b) Will participants be informed that their participation is voluntary?	Yes
c) Will participants be informed that they are free to withdraw at any time?	Yes
d) Will participants be informed of aspects relevant to their continued participation in the study?	Yes
e) Will participants' data remain confidential?	Yes
f) Will participants be debriefed?	Yes

If you have answered 'no' to all items in SECTION C1 and 'yes' to all questions in SECTION C2 the application will be processed through expedited review.

If you have answered "Yes" to one or more questions in Section C1, or "No" to one or more questions in Section C2, but wish to apply for expedited review, please make the case below. See research ethics website for an example "case for expedited review".

C3) **Case for Expedited Review –** *To be used if asking for expedited review despite answering YES to questions in C1 or NO to answers in C2.*

The interviews may involve the discussion of sensistive information. Many of the issues which are relevant to the study of caregiving could be considered sensitive. However, these are issues which are important to be studied and which can be discussed openly with researchers who are themselves tactful and sensitive. The PI has conducted, and supervised, many studies which have addressed sensitive issues. Participants are always made aware both in the information sheet and at the beginning of the interview that sensitive issues may arise and that they can withdraw from the study at any point, and recording can cease or be temporarily paused at the request of the participant. In general, participants do not volunteer for these types of study if they are not prepared to discuss issues which may be sensitive. Indeed, for many participants it is the opportunity to discuss such issues with an independent researchers which draws them to participate.

A mention must also be made of the fact that these interviews may be to a certain degree distressing. However, again the distress caused is no greater than that experienced in the course of normal life. Transitions out of marriage are by their nature distressing. But again, participants are made aware of this, and of the opportunity to withdraw or pause at any stage.

A variety of safeguards are put in place to meet the needs of participants should they be required. The PI has experience of dealing with unexpected outcomes. Participants are never left in a distressed state and interviews are designed to end on general advice giving by the participant to ensure a positive end to the interview. Participants are also always welcome to contact the researchers at later stages to give additional information, seek advice, or just for a chat.

SECTION D - PARTICIPANT DETAILS

D1) How many participants will be recruited?

Approximately 16 participants will be recruited - all those who volunteer will be interviewed if they meet inclusion criteria.

D2) How was the number of participants decided upon?

Guest et al., (2007) suggest that theme saturation can be obtained with 16 participants.

D3)

a) Describe how potential participants in the study will be identified, approached and recruited.

The PI has contact with a wide-range of organisations in the Merseyside area including social services, trade unions, religious organisations, Age Concern, luncheon clubs, support groups. In addition, any organisations where the target group might go will be approached. This type of recruitment has worked very well in the past. Members of the research team will approach appropriate organisations by phone, email or in person. If wished, the team will give a presentation to the organisation. Interested parties will receive an information sheet and an expression of interest form. They will then be contacted and the study explained again and if the prospective participant wishes to participate an mutually convenient time for interview will be made at a place most convenient for the participant. They will also be asked if they have friends, family or associates who might also be interested in participating. They will be given the information sheet and expression of interest form to pass on.

b) Inclusion criteria:

18 years and over. Able to give written informed consent. In active care of a relative with diagnosed dementia. Proficient English speakers.

c) Exclusion criteria:

Under 18. Physically or mentally too frail to participate. Spousal carers must be currently married. Not proficient in English.

d) Are any specific groups to be excluded from this study? If so please list them and explain why:

No

e) Give details for cases and controls separately if appropriate:

N/A

f) Give details of any advertisements:

An example of a recruitment poster is attached. These will be designed specifically for each sub-project.

D4) State the numbers of participants from any of the following groups and justify their inclusion

Children under 16 years of age:	0
Adults with learning disabilities:	0
Adults with dementia:	0
Prisoners:	0
Young Offenders:	0
Adults who are unable to consent for themselves:	0
Healthy Volunteers:	at least 15
Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, students of the PI or Co-applicants:	N6.
Other vulnerable groups (please list):	None

D5)

a) Describe the arrangements for gaining informed consent from the research participants.

Interested parties will receive an information sheet and an expression of interest form along with a pre-paid envelope which they can return. Before an interview commences, details of the project will be given to participants both orally and in writing. The process of written informed consent will be explained. Participants will be told they can withdraw at any time before, during or indeed after the interview. They will be given the consent form to read and then sign, one copy will be retained by them and the other kept by the interviewer.

b) If participants are to be recruited from any of the potentially vulnerable groups listed above, give details of extra steps taken to assure their protection, including arrangements to obtain consent from a legal, political or other appropriate representative in addition to the consent of the participant *(e.g. HM Prison Service for research with young offenders, Head Teachers for research with children etc.).*

N/A

c) If participants might not adequately understand verbal explanations or written information given in English, describe the arrangements for those participants (e.g. translation, use of interpreters etc.)

Participants will be proficient in English

d) Where informed consent is not to be obtained (including the deception of participants) please explain why.

N/A

D6) What is the potential for benefit to research participants, if any?

There is no intended benefit of participation in this study. However, the PI has found that many participants are glad to have taken part. For some people it is the only opportunity they have to talk frankly and openly about how they feel. They are also pleased to be doing something to help others in the same situation.

D7) State any fees, reimbursements for time and inconvenience, or other forms of compensation that individual research participants may receive. Include direct

payments, reimbursement of expenses or any other benefits of taking part in the research?

None.

SECTION E - RISKS AND THEIR MANAGEMENT

E1) Describe in detail the potential physical or psychological adverse effects, risks or hazards (minimal, moderate, high or severe) of involvement in the research for research participants.

There are unlikely to be any adverse physical effects of participation. There may be some minor distress. However, it is anticipated that these will be no greater than the participant meets during their every day life. Previous experience of the PI suggests that participants do not experience any long-lasting effects.

E2) Explain how the potential benefits of the research outweigh any risks to the participants.

Understanding the development of resilience over time in caregiving for dementia and how this varies by relationship type is essential if society is to provide effective and appropriate support for adults in terms of formal and informal care, health and welfare provision. The people who are the experts in the effects of caregiving are the people themselves. Without their experiences it is very difficult to understand what improvements society can make to the lives of people.

E3) Describe in detail the potential adverse effects, risks or hazards (minimal, moderate, high or severe) of involvement in the research for the researchers.

This research carries some minimal risk to the researchers. Discussion of sensitive and emotive issues are difficult. It is important that researchers are not over burdened. Interviewers will conduct no more than two interviews a day and five interviews a week. The PI, or other member of the research team will be available for debriefing at the end of each interviewing day. If the PI is working

alone she will put in place appropriate debriefing opportunities. The interviewer will always keep a mobile phone with them, and the place, time and expected duration of the interview will be kept in a diary.

E4) Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews/group discussions, or use of screening tests for drugs)?

YES ☒ NO ☐

- ***If Yes, give details of procedures in place to deal with these issues.***

These have been discussed above.

E5) Describe the measures in place in the event of any unexpected outcomes or adverse events to participants arising from their involvement in the project

The research team has a list of appropriate organisations which can be contacted wither by the participant or by the research team if requested by the participant. The project team will be available after the interview by phone, or if necessary in person, to speak to the participant. Adverse events will reported to the Research Governance Office within 24 hours.

E6) Explain how the conduct of the project will be monitored to ensure that it conforms with the study plan and relevant University policies and guidance.

There will be regular supervision between the PI and the research team. If the PI is working alone, she will seek an advisory group to monitor progress and procedures.

SECTION F - DATA ACCESS AND STORAGE

F1) Where the research involves any of the following activities at any stage (including identification of potential research participants), state what

measures have been put in place to ensure confidentiality of personal data (e.g. encryption or other anonymisation procedures will be used)

Electronic transfer of data by magnetic or optical media, e-mail or computer networks	Dictophone recording (see below). Back-up of interviews will also be kept on CD but this data will be anonymised. Any data transferred by email (interview transcripts) will be anonymised.
Sharing of data with other organisations	None
Export of data outside the European Union	None
Use of personal addresses, postcodes, faxes, e-mails or telephone numbers	These will be kept separately from the interview recordings and transcriptions. They will be kept in a locked filing cabinet. The diary with interview details will be kept in a locked room and destroyed when the study has been completed.
Publication of direct quotations from respondents	These will be anonymised and all identifying features changed. Participants will be informed that they may be quoted and can opt out if they wish.
Publication of data that might allow identification of individuals	None
Use of audio/visual recording devices	There will be audio recording of interviews. They will be transcribed promptly. Audio-recordings will be

	stored separately from transcripts on a passworded computer.
Storage of personal data on any of the following:	
Manual files	Transcripts will be paper based and text based but will be anonymised.
Home or other personal computers	N/A
University computers	All data stored on this will be anonymised.
Private company computers	N/A
Laptop computers	The PI has a University laptop. All data stored on this will be anonymised.

F2) Who will have control of and act as the custodian for the data generated by the study?

K M Bennett

F3) Who will have access to the data generated by the study?

Members of the research team

F4) For how long will data from the study be stored?

15 years

SECTION G - CHECKLIST OF ENCLOSURES

Study Plan / Protocol	No
Recruitment advertisement	N/A
Participant information sheet	Yes
Participant Consent form	Yes
Research Participant Advocate Consent form	N/A
Evidence of external approvals	N/A
Questionnaires on sensitive topics	N/A
Interview schedule	Yes
Debriefing material	N/A
Other (please specify)	N/A

From: Psychology Ethics <psyethic@liverpool.ac.uk>

Date: 24 June 2011 15:37:16 GMT+01:00

To: "Bennett, Kate" <kmb@liverpool.ac.uk>

Subject: PSYC-1011-101-Kate Bennett-The development of resilience over time among caregivers of relatives with dementia: variations and mediations within and between spousal and parental relationships.

Kate, just one comment from the reviewers that the forms must be proof-read before going to participants as there may be some typos (e.g. imminent is misspelt in the info sheet).

Dear Kate

Your Ethics Application has been approved (with no need for changes) by the School of Psychology Ethics Committee:

Reference: PSYC-1011-101

Principal Investigator: Kate Bennett

Project Title: The development of resilience over time among caregivers of relatives with dementia: variations and mediations within and between spousal and parental relationships.

First Reviewer: Julian Pine

Second Reviewer: Caroline Rowland

As the principal investigator (PI), it is your responsibility to keep the final, approved version of your Ethics Application form for this project and to provide it to any students or other collaborators who also work on this project *before* they begin work on the project.

All undergraduate and taught masters students will need to bind a hard copy of this Ethics Application approval email *and* a copy of your final, approved Ethics Application form into any work that they submit based on this project (e.g., third year projects and Master's dissertation projects). They will also need to bind into their work hard copies of any participant information sheets, consent forms, and debriefing forms used during the project.

Rebecca Lawson

Chair, School of Psychology Ethics Committee

Appendix 2

Ethics form and approval email: Chapter 5 study

UNIVERSITY OF LIVERPOOL

COMMITTEE ON RESEARCH ETHICS

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING

HUMAN PARTICIPANTS, HUMAN DATA, OR HUMAN MATERIAL

This application form is to be used by researchers seeking approval from the **University Committee on Research Ethics** or from an approved **School Research Ethics Committee**.

Applications to the University Research Ethics Sub-Committees, with the specified attachments, should be **submitted electronically to** ethics@liv.ac.uk. Applications to an approved School / Departmental Committee should be submitted to their local address, available at http://www.liv.ac.uk/researchethics/deptcommittees.htm.

RESEARCH MUST NOT BEGIN UNTIL ETHICAL APPROVAL HAS BEEN OBTAINED

This form must be completed by following the guidance notes, accessible at www.liv.ac.uk/researchethics.

Please complete every section, using N/A if appropriate.

Incomplete forms will be returned to the applicant.

BEFORE COMPLETING YOUR APPLICATION PLEASE CONFIRM WHAT APPROVAL YOU ARE SEEKING (please check):

a) Expedited review of an individual research project ☒
b) Full committee review of an individual research project ☐
c) Expedited generic* approval ☐
d) Committee review generic* approval ☐

*to cover a cohort of projects using similar methodologies. Boundaries of the research must be defined clearly. Approval may be granted for up to 5 years and will be subject to annual review.

Office Use Only *(for final hard copies)*

Reference Number: RETH

Date final copy received:

Approval decision:

Approved – no conditions ☐

Committee ☐

Chairs Action ☐

Expedited ☐

Approved with conditions ☐

Committee ☐

Chairs Action ☐

Expedited ☐

Declaration of the:

Principal Investigator ☒ **OR** **Supervisor and Student Investigator** ☐
(please check as appropriate)

- The information in this form is accurate to the best of my knowledge and belief, and I take full responsibility for it.

- I have read and understand the University's Policy on Research Ethics

- I undertake to abide by the ethical principles underlying the Declaration of Helsinki and the University's good practice guidelines on the proper conduct of research, together with the codes of practice laid down by any relevant professional or learned society.

- If the research is approved, I undertake to adhere to the study plan, the terms of the full application of which the REC has given a favourable opinion, and any conditions set out by the REC in giving its favourable opinion.

- I undertake to seek an ethical opinion from the REC before implementing substantial amendments to the study plan or to the terms of the full application of which the REC has given a favourable opinion.

- I understand that I am responsible for monitoring the research at all times.

- If there are any serious adverse events, I understand that I am responsible for immediately stopping the research and alerting the Research Ethics Committee within 24 hours of the occurrence, via ethics@liv.ac.uk.

- I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.

- I understand that research records/data may be subject to inspection for audit purposes if required in future.

- I understand that personal data about me as a researcher in this application will be held by the University and that this will be managed according to the principles established in the Data Protection Act.

- I understand that the information contained in this application, any supporting documentation and all correspondence with the Research Ethics Committee relating to the application, will be subject to the provisions of the Freedom of Information Acts. The information may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

- I understand that all conditions apply to any co-applicants and researchers involved in the study, and that it is my responsibility to ensure that they abide by them.

- **For Supervisors**: I understand my responsibilities as supervisor, and will ensure, to the best of my abilities, that the student investigator abides by the University's Policy on Research Ethics at all times.

- **For the Student Investigator**: I understand my responsibilities to work within a set of safety, ethical and other guidelines as agreed in advance with my supervisor and understand that I must comply with the University's regulations and any other applicable code of ethics at all times.

Signature of Principal Investigator ☒ **or** **Supervisor** ☐**:**
.....

Date: (16/05/2013)

Print Name: Kate M Bennett

Signature of Student Investigator: .....

Date: (dd/mm/yyyy)

Print Name: Kate M Bennett

SECTION A - IDENTIFYING INFORMATION

A1) Title of the research (PLEASE INCLUDE A SHORT LAY TITLE IN BRACKETS).

Exploring the age-related 'positivity' effect in older dementia caregivers.

A2) Principal Investigator ☒ **OR** **Supervisor** ☐ **(please check as appropriate)**

Title:	Dr	**Staff number:**	
Forename/Initials:	Kate	**Surname:**	Bennett
Post:	Reader	**Department:**	Psychology
Telephone:	0151 794 1410	**E-mail:**	kmb@liv.ac.uk

A3) Co-applicants (including student investigators)

Title and Name	Post / Current programme (if student investigator)	Department/ School/Institution if not UoL	Phone	Email
Mr Warren Donnellan	Demonstrator	Psychology	0151 795 0647	wjd@liv.ac.uk

SECTION B - PROJECT DETAILS

B1) Proposed study dates and duration (RESEARCH **MUST NOT BEGIN** UNTIL ETHICAL APPROVAL HAS BEEN OBTAINED)

Please complete as appropriate:

EITHER

a) Starting as soon as ethical approval has been obtained ☒ (please check if applicable)

Approximate end date:	July 2018

OR

b) Approximate dates:

Start date:		**End date**:	

B2) Give a full lay summary of the purpose, design and methodology of the planned research.

The proposed research aims to add to the current understanding of emotional processing. Previous studies have shown that when a series of words are presented to participants, emotionally valenced words are recalled at the same rate when the word list is followed by an unexpected free recall task. Research has shown that age brings about a robust difference in recall and processing, with older adults recalling more positively valenced words by deriving more 'deep' emotional meaning and younger adults recalling more negatively valenced words by deriving more 'shallow' emotional meaning; this has been termed the 'positivity' effect. Qualitative research has also been conducted on positivity in the context of dementia care, with some family caregivers making an active effort to remain positive in their role. The current study aims to investigate whether the 'positivity' effect can explain this tendency to stay positive in the caregiving role; specifically, whether the bias towards positive information holds in older adults despite the typically negative circumstances surrounding dementia caregiving.

The study utilises a mixed design so participants will be asked to either assess the presented words using 'shallow' or 'deep' processing. Half of the younger participants will be assigned to the 'shallow' processing group and half to the 'deep' processing group, and the same for the older participants. In the 'shallow' processing groups, participants will be asked to simply state how many letters are in the word or how many vowels appear in the word or other descriptive properties of the word. In the 'deep' processing group, participants may be asked to guess a person's reaction if they were to say the word to them, or asked if the word may be considered offensive or upsetting to another person or other affective properties of the word. The

presentation order of words will be psuedo-randomised to control for primacy and recency effects. After assessing the words (36 words will be presented), participants will be asked to write down as many words as they can remember. Based on previous research, it is expected that emotionally valenced words will be recalled more readily than emotionally neutral words and positively valenced words will be recalled more by older participants and negatively valenced words will be recalled more by younger participants. Words will be presented to participants on a laptop using PowerPoint slides and participants will respond to 'deep' or 'shallow' processing on a sheet of paper. Word recall will consist of writing the remembered words on the back of the response sheet. Spelling is not important, and participants will be informed of this. The independent variables will be level of processing (deep or shallow), word valence type (positive, negative and neutral, 12 words in each group). Words will be selected from a database created by Eilola, Havelka and Sharma (2007). The criteria for word selection will be applied to ensure an even number of positive, negative and neutral words, as well as having a range of word lengths and familiarity. The study will follow a similar methodology to Anooshian and Hertel (1994).

Participants will be approached across the campus of the University of Liverpool. Older participants will be approached through a number of organisations in the Merseyside area, including social services, trade unions, religious organisations, Age UK, luncheon clubs, and support groups. Members of the research team will approach appropriate organisations by phone, e-mail or in person. Those interested in participating will be presented with an information sheet about the study including what is expected of them, their rights and what will happed with their data. If they agree to continue, they will be asked to sign a consent form before the task begins. At the end of the recall test, participants will be fully debriefed, and given contact details of the Ethics Research Governance Officer and the study supervisor. They will also be given contact details of helplines if they have found any of the words upsetting or offensive. Participants will be informed that they can ask any questions they may have before, during and after the data collection. No identifable information will be collected; demographic data such as age and gender will be collected, but participants will be reminded that this is voluntary and they have the right to withdraw at any stage.

B3) List any research assistants, sub-contractors or other staff not named above who will be involved in the research and detail their involvement.

N/A

B4) List below all research sites, and their Lead Investigators, to be included in this study.

Research Site	Individual Responsible	Position and contact details
University of Liverpool campus	Dr Kate Bennett	as above

B5) Are the results of the study to be disseminated in the public domain?

YES ☒ NO ☐

- ***If not, why not?***

B6) Give details of the funding of the research, including funding organisation(s), amount applied for or secured, duration, and UOL reference

Funding Body	Amount	Duration	UoL Reference
N/A			

B7) Give details of any interests, commercial or otherwise, you or your co-applicants have in the funding body.

N/A

SECTION C - EXPEDITED REVIEW

C1)

a) Will the study involve recruitment of participants outside the UK?	No
b) Does the study involve participants who are particularly vulnerable or unable to give informed consent? *(e.g. children, people with learning or communication disabilities, people in custody, people engaged in illegal activities such as drug-taking, your own students in an educational capacity) (Note: this does not include secondary data authorised for release by the data collector for research purposes.)*	No
c) Will the study require obtaining consent from a "research participant advocate" (for definition see guidance notes) in lieu of participants who are unable to give informed consent? *(e.g. for research involving children or, people with learning or communication disabilities)*	No
d) Will it be necessary for participants, whose consent to participate in the study will be required, to take part without their knowledge at the time? *(e.g. covert observation using photography or video recording)*	No
e) Does the study involve deliberately misleading the participants?	No
f) Will the study require discussion of sensitive topics that may cause distress or embarrassment to the participant or potential risk of disclosure to the researcher of criminal activity or child protection issues? *(e.g. sexual activity, criminal activity)*	No

g) Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No
h) Will samples (e.g. blood, DNA, tissue) be obtained from participants?	No
i) Is pain or more than mild discomfort likely to result from the study?	No
j) Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	No
k) Will the study involve prolonged or repetitive testing?	No
l) Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	No

C2)

a) Will the study seek written, informed consent?	Yes
b) Will participants be informed that their participation is voluntary?	Yes
c) Will participants be informed that they are free to withdraw at any time?	Yes
d) Will participants be informed of aspects relevant to their continued participation in the study?	Yes
e) Will participants' data remain confidential?	Yes
f) Will participants be debriefed?	Yes

If you have answered 'no' to all items in SECTION C1 and 'yes' to all questions in SECTION C2 the application will be processed through expedited review.

If you have answered "Yes" to one or more questions in Section C1, or "No" to one or more questions in Section C2, but wish to apply for expedited review, please make the case below. See research ethics website for an example "case for expedited review".

C3) Case for Expedited Review – *To be used if asking for expedited review despite answering YES to questions in C1 or NO to answers in C2.*

This study requires participants to view words, some of which they may find mildly upsetting. Words to be presented to participants will be selected from a validated database, and have been assessed for familiarity. It is therefore suggested that although some words may be considered upsetting, all words may be heard on a day to day basis outside of the study. Also, the academic and experimental situation in which the words are presented ensure that alternative contexts in which some of the words may be used (e.g. aggression) are not present, diluting the situational emotional context and ensuring focus is on the emotional content of the target word. This study uses similar methodology and the same list of words as a study previously approved (ref: PSYC07080205).

SECTION D - PARTICIPANT DETAILS

D1) How many participants will be recruited?

300

D2) How was the number of participants decided upon?

Similar to previous research using similar methodology

D3)

a) Describe how potential participants in the study will be identified, approached and recruited.

Opportunity sampling will be utilised. Younger participants will be selected and approached on the basis that they are in University of Liverpool facilities. Older participants will be identified through a wide variety of organisations in the Merseyside area, including social services, trade unions, religious organisations, Age UK, luncheon clubs, and support groups. This type of recruitment has worked very well in the past. Members of the research team will approach appropriate organisations by phone, e-mail or in person. Participants will be asked if they would mind participating and given an information sheet and the opportunity to ask any questions they may have. If the prospective participant wishes to participate a mutually convenient time will be made. The experimental paradigm used consists of a laptop and a sheet of paper and so is portable. This means that the experiment is flexible and can take place at any quiet place most convenient for those participants (particularly carers) for whom time may be constrained. They will also be asked if they have friends, family or associates who might also be interested in participating. They will be given the information sheet and expression of interest form to pass on.

b) Inclusion criteria:

Adults over the age of 18.

c) Exclusion criteria:

Those under 18 years of age.

d) Are any specific groups to be excluded from this study? If so please list them and explain why:

N/A

e) Give details for cases and controls separately if appropriate:

N/A

f) Give details of any advertisements:

N/A

D4)

a) State the numbers of participants from any of the following vulnerable groups and justify their inclusion

Children under 16 years of age:	0
Adults with learning disabilities:	0
Adults with dementia:	0
Prisoners:	0
Young Offenders:	0
Adults who are unable to consent for themselves:	0
Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, students of the PI or Co-applicants:	0
Other vulnerable groups (please list):	0

b) State the numbers of healthy volunteer participants:

Healthy Volunteers	**100**

D5)

a) Describe the arrangements for gaining informed consent from the research participants.

Potential participants will be approached and verbally asked if they are willing to participate in the study. If potential participates are wililng to participate, they will be presented with an information sheet and given the opportunity to ask the researcher any questions they may have. If the potential participants are satisfied and still willing to participate, they will be asked to sign a consent form before their data is collected. Participants will also be debriefed and given the contact details of the principal investigator, relevant helpful information and again the opportunity to ask any questions they may have.

b) If participants are to be recruited from any of the potentially vulnerable groups listed above, give details of extra steps taken to assure their protection, including arrangements to obtain consent from a legal, political or other appropriate representative in addition to the consent of the participant *(e.g. HM Prison Service for research with young offenders, Head Teachers for research with children etc.).*

N/A

c) If participants might not adequately understand verbal explanations or written information given in English, describe the arrangements for those participants (e.g. translation, use of interpreters etc.)

If any participants do not fully understand what is expected of them or are not satisfied with their participation, data collection will not occur.

d) Where informed consent is not to be obtained (including the deception of participants) please explain why.

N/A

D6) What is the potential for benefit to research participants, if any?

There is no direct benefit of participating in the current study, but participants may gain insight into psychological research being conducted at the university.

D7) State any fees, reimbursements for time and inconvenience, or other forms of compensation that individual research participants may receive. Include direct payments, reimbursement of expenses or any other benefits of taking part in the research?

N/A

SECTION E - RISKS AND THEIR MANAGEMENT

E1) Describe in detail the potential physical or psychological adverse effects, risks or hazards (minimal, moderate, high or severe) of involvement in the research for research participants.

There is a minimal risk that participants will find the subject matter upsetting. Participants will be informed of the nature of the study before they are presented with any stimuli, and asked to refrain from participating if they find the subject matter sensitive. They will be told of their right to withdraw at any time.

E2) Explain how the potential benefits of the research outweigh any risks to the participants.

The risks to participants are minimal and are outweighed by the potential benefits of understanding emotional processing in the context of dementia caregiving.

E3) Describe in detail the potential adverse effects, risks or hazards (minimal, moderate, high or severe) of involvement in the research for the researchers.

It is very doubtful that this study will lead to any physical or psychological adverse effects, risks or hazards for the researchers (i.e. predicted adverse effects are minimal). However, although it is not anticipated that adverse effects will occur, if they do, the study will be halted immediately and the problems will be reported to the sub-committee within 24 hours of their occurrence through the Research Governance Officer (ethics@liverpool.ac.uk).

E4) Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews/group discussions, or use of screening tests for drugs)?

YES ☐ NO ☒

- ***If Yes, give details of procedures in place to deal with these issues.***

N/A

E5) Describe the measures in place in the event of any unexpected outcomes or adverse events to participants arising from their involvement in the project

Although it is not anticipated that adverse effects will occur, if they do, the study will be halted immediately and the problems will be reported to the PI and to the sub-committee within 24 hours of their occurrence through the Research Governance Officer (ethics@liverpool.ac.uk). Also, the researcher will be aware of all fire and health and safety regulations in the building (s) and the University Security Control number (if in University building). Participants will be given the contact details of the PI and reseacher to use in the event of any unforseen adverse effects. They will also be given the contact details fo the governance office to be used in the event of any complaints, or issues that cannot be resolved by the researchers.

E6) Explain how the conduct of the project will be monitored to ensure that it conforms with the study plan and relevant University policies and guidance.

Student investigators will be fully breifed by the principal investigator before any data is collected. Student investigators will meet regularly with the principal investigator to discuss progress, problems and findings. Both parties are aware of the university ethics policy and the BPS ethical research policy.

SECTION F - DATA ACCESS AND STORAGE

F1) Where the research involves any of the following activities at any stage (including identification of potential research participants), state what measures have been put in place to ensure confidentiality of personal data (e.g. encryption or other anonymisation procedures will be used)

Electronic transfer of data by magnetic or optical media, e-mail or computer networks	Data will be anonymised before spreadsheet entry and electronic storage
Sharing of data with other organisations	N/A

Export of data outside the European Union	N/A
Use of personal addresses, postcodes, faxes, e-mails or telephone numbers	N/A
Publication of direct quotations from respondents	N/A
Publication of data that might allow identification of individuals	N/A
Use of audio/visual recording devices	N/A
Storage of personal data on any of the following:	
Manual files	Manual files will be coded for anonymity and identifying codes will be kept separately in a locked filing cabinet accessible by the principal investigator only.
Home or other personal computers	Only anonymised data to be electronically stored.
University computers	Only anonymised data to be electronically stored.
Private company computers	N/A
Laptop computers	Only anonymised data to be stored electronically stored

F2) Who will have control of and act as the custodian for the data generated by the study?

Kate M Bennett

F3) Who will have access to the data generated by the study?

Principal investigator and named students only.

F4) For how long will data from the study be stored?

Five years in accordance with conditions in academic journals.

SECTION G – PEER REVIEW

G1)

a) Has the project undergone peer review?

YES ☐ NO ☒

b) If yes, by whom was this carried out? *(please enclose evidence if available)*

SECTION G - CHECKLIST OF ENCLOSURES

Study Plan / Protocol	No
Recruitment advertisement	N/A
Participant information sheet	Yes
Participant Consent form	Yes
Research Participant Advocate Consent form	N/A
Evidence of external approvals	N/A
Questionnaires on sensitive topics	N/A
Interview schedule	N/A
Debriefing material	Yes
Other (please specify)	N/A
Evidence of peer review (If G1 = Yes)	N/A

Dear Kate

I am pleased to inform you that IPHS Research Ethics Committee has approved your application for ethical approval. Details and conditions of the approval can be found below.

Ref: IPHS-1213-LB-092

PI / Supervisor: Kate Bennett

Title: Exploring the age-related `positivity' effect in older dementia caregivers

First Reviewer: Sophie Wuerger

Second Reviewer: Margaret Wilson

Date of Approval: 19.6.13

The application was APPROVED subject to the following conditions:

1 All serious adverse events must be reported to the Sub-Committee within 24 hours of their occurrence, via the Research Governance Officer (ethics@liv.ac.uk).

2 This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, IPHS REC should be notified as follows. If it is proposed to make an amendment to the research, you should notify IPHS REC by following the Notice of Amendment procedure outlined at http://www.liv.ac.uk/researchethics/amendment%20procedure%209-08.doc.

3 If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the Institute's Research Ethics Office at iphsrec@liverpool.ac.uk in order to notify them of a change in PI / Supervisor.

Best Wishes

Liz Brignal

Secretary, IPHS Research Ethics Committee

Email: iphsrec@liv.ac.uk

Appendix 3

Information sheet and consent form: Qualitative studies

Caregiving for a relative with dementia: changes in psychological wellbeing over time

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thank you for reading this.

This study will examine the experience of caring for a spouse with dementia; particularly the development of resilience and how this manifests itself over time. With the number of new people diagnosed with dementia projected to treble by 2050 there is an urgent and imminent need for an increased understanding of the positives of caregiving (resilience) away from the more popular detriments. Understanding and publisicing this cause may also go some way to lessening the burden felt on informal and formal care (e.g. care homes).

If you agree to take part you will be asked to complete a series of questionnaires measuring psychological resilience, general health, social support, marital quality and health and welfare service use. You will also be interviewed on a one-to-one basis about your experiences of being a Carer. Participation is entirely voluntary and you can decide to withdraw from the research at any time. The data will be kept securely unless you request it to be destroyed. There is no intended benefit for you in taking part in this study although

many participants are glad to have taken part. For some people it is the only opportunity they have to talk frankly and openly about how they feel. They are also pleased to be doing something to help others in the same situation.

If you are unhappy, or if there is a problem, please feel free to let us know using the contact details provided below and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Governance Officer on 0151 794 8290 (ethics@liv.ac.uk). When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make. Participants taking part in a University of Liverpool ethically approved study will have cover.

Please contact the researchers with any questions you may have:

Warren Donnellan:

Email: (wjd@liv.ac.uk) Phone: 0151 795 0647

Alternatively you may contact the research supervisor, **Dr Kate Bennett** on the contact details below:

Dr Kate M Bennett
Senior Lecturer
Chartered Health Psychologist
HPC Practitioner Psychologist
School of Psychology
University of Liverpool
Eleanor Rathbone Building
Bedford Street South
Liverpool L69 7ZA
UK

Tel: 0151 794 1410
Tel: 0151 794 2957
Fax: 0151 794 6937
http://www.liv.ac.uk/~kmb/
http://www.liv.ac.uk/Psychology/

UNIVERSITY OF LIVERPOOL

CONSENT FORM

Title of Research Project:	Caregiving for a relative with dementia: changes in psychological wellbeing over time
Researcher(s):	Warren J. Donnellan Kate M. Bennett

	Please initial box
1. I confirm that I have read and have understood the information sheet dated 2012 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand that my interview will be audio-recorded and later transcribed.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.	☐
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.	☐
4. I agree to take part in the above study.	☐
5. I am willing for quotations from my interview to be used in presentations and publications by the Researcher on the understanding that all identifying features will be removed and I cannot be identified	☐

Participant Name	Date	Signature
Researcher	Date	Signature

The contact details of lead researchers (Principal Investigators) are:

Warren Donnellan
Email: wjd@liv.ac.uk **Phone:** 0151 795 0647

Kate Bennett
Email: kmb@liv.ac.uk **Phone:** 0151 794 2957

School of Psychology, University of Liverpool, Eleanor Rathbone Building, Bedford Street South, Liverpool L69 7ZA.

Appendix 4

Information sheet and consent form: Chapter 5 study

Participant Information Sheet

Study Title: Age-related emotional processing

You are being invited to take part in a research project. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything you do not understand. Please also feel free to discuss this with your friends if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

This study is looking to see whether emotional words are perceived differently from emotionally neutral words and how this varies by age and care status. Emotional words may be positively or negatively charged, and this may also have an effect on how people perceive them.

Eligibility criteria: People aged 18-28, 40-60, or 65-75 who: i. Are non-carers, or: ii. Currently provide care to a relative with dementia. Participants must have no history of neurological or psychological disorder. **All personal information will be kept strictly confidential. You cannot be identified by your responses. We record this data for demographic purposes only.**

If you agree to take part, you will be shown a series of words, and asked to write down either how many letters are in the word, or if the word is emotionally positive, negative or neutral. The whole test should take about 10 minutes. You do not have to take part if you don't want to, and can request to have your data removed from the study at any point after you have taken part. You do not have to give any reason for not taking part or withdrawing.

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Kate Bennett (0151 794 1410) kmb@liv.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Governance Officer on 0151 794 8290 (ethics@liv.ac.uk). When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

If you agree to participate, please now sign the Participant Consent Form.

UNIVERSITY OF LIVERPOOL

Title of Research Project:	Age-related emotional processing
Researcher(s):	K. Bennett, W. Donnellan, D. Farrar, L. Evans, J. Benyon, A. Equizi, A. Ewart, R. Bergin, Z. Blackburn.

	Please initial box
6. I confirm that I have read and have understood the information sheet dated February 2016 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.	☐
8. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.	☐
9. I agree to take part in the above study.	☐

Participant Name	Date	Signature
Researcher	Date	Signature

The contact details of lead Researcher (Dr Kate Bennett) are:

Eleanor Rathbone Building
Bedford Street South
University of Liverpool
L69 7ZA
Tel: 0151 794 1410
Email: kmb@liv.ac.uk.

Appendix 5

Testing booklet: Chapter 5 study

Please fill out the information below before completing the study.

Age:

Gender: Male/Female

Years of Education (high school onwards): ……

Current mood (baseline):

With 1 being very bad and 7 being very happy, please indicate your current mood on the scale below.

1 2 3 4 5 6 7

Please answer these questions below by circling the corresponding answers as each word card is displayed.

1. How many letters does this word have?

3-4	5-6	7-8	9-10

2. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

3. How many letters does this word have?

3-4	5-6	7-8	9-10

4. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

5. How many letters does this word have?

3-4	5-6	7-8	9-10

6. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

7. How many letters does this word have?

3-4	5-6	7-8	9-10

8. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

9. How many letters does this word have?

3-4	5-6	7-8	9-10

10. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

11. How many letters does this word have?

3-4	5-6	7-8	9-10

12. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

13. How many letters does this word have?

3-4	5-6	7-8	9-10

14. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

15. How many letters does this word have?

3-4	5-6	7-8	9-10

16. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

17. How many letters does this word have?

3-4	5-6	7-8	9-10

18. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

19. How many letters does this word have?

3-4	5-6	7-8	9-10

20. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

21. How many letters does this word have?

3-4	5-6	7-8	9-10

22. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

23. How many letters does this word have?

3-4	5-6	7-8	9-10

24. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

25. How many letters does this word have?

3-4	5-6	7-8	9-10

26. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

27. How many letters does this word have?

3-4	5-6	7-8	9-10

28. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

29. How many letters does this word have?

3-4	5-6	7-8	9-10

30. How many times would you come across this word in the space of a week?

1-2	2-3	4-5	6-7

Current mood:

With 1 being very bad and 7 being very happy, please indicate your current mood on the scale below. 1 2 3 4 5 6 7

Please use the following scale to indicate how much you agree or disagree with each of the statements. Please tick only one box on each line.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. When I make plans I follow through with them.					
2. I usually manage one way or another.					
3. I am able to depend on myself more than anyone else.					
4. I feel that I can handle many things at a time.					
5. I keep interested in things.					
6. In an emergency, I'm someone people generally can rely on.					
7. I'm not good at guiding the course of a conversation with several others.					
8. If I need help in carrying off a plan of mine, it's usually difficult to get others to help.					
9. I have no trouble making and keeping friends.					
10. If there's someone I want to meet I can usually arrange it.					
11. I find it easy to play an important part in most group situations.					
12. On the whole, I am satisfied with myself.					
13. I feel that I have a number of good qualities.					
14. I take a positive attitude towards myself.					
15. I feel that I'm a person of worth, at least on an equal plane with others.					
16. I feel I do not have much to be proud of.					

17. At times I think I am no good at all.					
18. I wish I could have more respect for myself.					
19. All in all, I am inclined to feel that I am a failure.					

CARERS ONLY

Current care status:

I provide care at home [ ]

I provide care at home with respite [ ]

Other (please state) [ ] ……

Please state <u>which relative</u> you provide care for (e.g. spouse, parent, etc)

……

Did the care recipient receive a <u>formal diagnosis</u>? If so, please state which diagnosis was given.

Yes [ ] No [ ] Please state …….

For <u>how many years</u> have you provided care to the care recipient? …… years

How regularly would you say you provide care to the care recipient <u>in an average week</u>?

Rarely (1-2 days a week) [ ]

Occasionally (3-4 days a week) [ ]

Most of the time (4-5 days a week) [ ]

All of the time (6-7 days a week) [ ]

Please use the space below to tell us about the nature of the care that you provide to the care recipient, e.g. getting the newspaper, washing/bathing, etc.

……

……..……

……..…….....……

……

……..……

……..……

……..……

……..……

……..

Appendix 6

Example recruitment poster

Would you like to take part in a research study?

Carers of People with Dementia

Do you care for a family member with dementia?

CONTACT DETAILS

Principle Investigator:
Dr Kate Bennett
School of Psychology
University of Liverpool
Eleanor Rathbone Building
Bedford Street South
Liverpool L69 7ZA

To contact us:
Phone: 0151 795 0647
E-mail: wjd@liv.ac.uk

We are looking to understand more about the experiences of being a **Carer**, particularly how people deal with the challenges of **dementia** care.

The study will last for around **15 minutes** and can be at a time and place of your choice, such as at your local club, the university or even your home.

We hope that this research may allow for us to make recommendations to other **people in the same situation** as well as to those who work in health and welfare services.

Please let us know if you are interested in taking part or would like more information.

UNIVERSITY OF LIVERPOOL

Appendix 7

Participant information spreadsheet

			Transition			Transcribed	Notes
Participant	Pseudonym	Time point	At home	In care	Bereaved		
1	Mrs W.	T1	■			■	
		T2		■		■	
2	Mrs C.	T1	■			■	
		T2			■	■	
3	Mrs Wi.	T1	■			■	
		T2		■		■	
4	Mrs F.	T1	■			■	Participant deceased at T2
5	Mrs L.	T1			■	■	Already widowed
6	Mr G.	T1	■			■	
		T2	■			■	
7	Mrs Gr.	T1		■		■	
		T2			■	■	
8	Mrs Go.	T1	■			■	
		T2			■	■	
9	Mrs O.	T1	■			■	
		T2			■	■	
10	Mrs S.	T1	■			■	Untraceable
11	Mr Go.	T1	■			■	
		T2	■			■	
12	Mr Wh.	T1	■			■	
		T2			■	■	
13	Mr H.	T1	■			■	
		T2	■			■	
14	Mrs P.	T1	■			■	
		T2		■		■	
16	Mrs A.	T1		■		■	Friend carer - not spousal
17	Mrs Lg.	T1	■			■	
		T2	■			■	
18	Mrs Wk.	T1			■	■	Already widowed

19	Mrs Hn.	T1					
		T2					
21	Mr N.	T1					Untraceable
22	Mr Gr.	T1					
23	Mrs H.	T1					
24	Mrs La.	T1					
25	Mr Ha.	T1					
26	Mrs Cl.	T1					

Appendix 8

Time 1 home carer interview schedule

Spousal Schedule – T1 At home

The development of resilience among spousal caregivers:

Thank you for agreeing to talk about your experience of being a Carer. I am interested in your own personal experience which may be different from other people's, so tell me what it has been like for you. I would like to record the conversation with your permission. We will be able to arrange an opportunity for you to hear the recording if you would like. Should you wish to stop the interview at any time, or take a break, please tell me. Because the topic of our discussions is sensitive I can assure you that it will remain confidential.

I would like first of all to ask you half a dozen factual questions, and then ask you some more open questions about your experiences of being a Carer.

Section A

NOTE: Ongoing homecare/Already bereaved/Already institutionalised/Periodic Respite.

1. Can I just take your surname? When were you born? Where were you born? (Ethnicity) NOTE: gender

2. How long have you been married?

3. How long have you been caring for your wife/husband?

4a. Do you have, or have you had, any children?

4b. (If yes to 4a) How many?

5a. (If yes to 4a) do you have, or have you had, any grandchildren?

5b. (If yes to 5a) How many?

6a. (If yes to 5a) do you have, or have you had any great -grandchildren?

6b. (If yes to 6a) How many?

7a What was your job?

7b What was your wife/husband's job?

Section B

I would now like to ask you about **before your wife/husband was diagnosed with dementia**.

8. What was life like?

8a. Did you have any your own hobbies?

Prompts: Work? Interests?

8b. Describe a typical day spent with your husband/wife.

Prompt: What would you do together? e.g. Days out

8c. What would you say your marriage was like? (*before diagnosis)

Prompt: How did you get on together?

Did you have fun?

Did you disagree?

Can you tell me more?

8d. What roles and responsibilities did you have in the family?

Prompt: How did you divide household tasks between yourself and your husband/wife?

Were they independent?

Housework

Home maintenance

Finance

Car

8e. Who would you have turned to for someone to talk to? (see below)

Prompt: Husband/wife? Anyone other than your spouse?

If not, did you want someone to talk to? Did you bottle things up?

Ask participant to fill in a copy of the first support diagram.

I'd like to ask about the various kinds of support you receive at different stages.

Prompts: Informal, e.g. Friends, family, neighbours. Formal, e.g. Support workers/CPN/Doctors.

Section C

I would now like to ask you to think about the weeks **after s/he was first diagnosed with dementia**. I know this might be painful, so we can take it slowly and we can stop if you like.

9a. How did you feel?

Prompt: how did you react?

what was your mood like?

did your feel good or bad?

what happened as the days passed?

how were you with other people?

9b. How did you come to take the role of caring for your wife/husband?

Prompt: (e.g. instead of nurses)

were you already looking after, caring for or nursing her/him?

Division of labour with children/grandchildren? Anyone else?

can you tell me more?

9c. Thinking about your roles and responsibilities in the family, how did they first change (if at all) following the diagnosis of your husband/wife?

Prompt: Who took over the responsibilities of your husband/wife?

Think about: cooking, cleaning etc

Housework

Home maintenance

Finance

Car

9d. Did the kinds of support you received change at all?

Prompt: New people? Someone other than your spouse? Family? Friends

Why did you choose this person? If not, would you have wanted someone?

Refer to support diagram. If someone new, add them.

Section D

I would like to ask you to think about what it is like now?

10a. How do you spend your typical day? (<u>on own - if at all - and with husband/wife</u>)

Prompt: what about the household chores?

do you see or go out with family or friends?

how do you get around? Public transport, cash etc

do you have people you would consider true friends?

<u>Would you say that you do anything new at all?</u>

10b. How do you feel about that? (and generally)

Prompt: how are you?

what is your mood like?

do you feel better/worse/or the same?

how are you with other people?

can you tell me more?

10c. What is your relationship like now?

Prompts: better/worse? Do you disagree more/less?

10d. Thinking about your roles and responsibilities in the family, <u>what are they now, and how have they changed?</u>

Prompts: What do you do for your husband/wife?

Would you say you have assumed more responsibilities?

Cooking, cleaning

Housework

Home maintenance

Finance

Car

10e. Are the kinds of support you receive different now than they used to be?

Prompt: Anyone new? Do they help out too?

<u>Ask participant to fill in a copy of the second support diagram. Compare.</u>

10f. What has changed <u>most</u> from when your wife/husband was first diagnosed with dementia?

Prompt: can you tell me more?

did you say (?)

in what way.....

11. Some people become particularly successful at being a carer and we are trying to understand how.

People say that 'time heals'. What do you think?

Has that been your own experience?

Was there a particular occasion which you could say was a 'turning point', after which being a carer became easier?

Or was it a gradual process?

Or maybe there were a series of smaller but identifiable steps which led to life being easier?

What personal characteristics helped you?

Which people, or perhaps events or places, were particularly helpful? (e.g. support groups?)

12. Is there anything else you would like to talk about at this stage?

Prompts: Anything I forgot to ask?

Things you think I should be asking about?

Things you wouldn't say in the group? (personal, intimate)

How should I ask these questions?

Section E

I would now like to return to our earlier interview and ask you some more general questions.

13a. What advice would you give someone in the same situation as yourself?

13b. What would make life easier for you?

13c. What would you like the government or local authority to do for Carers?

Appendix 9

Time 2 continuing home carer interview schedule

Spousal Schedule – T2 At home

The development of resilience among spousal caregivers:

Thank you for agreeing to talk about your experience of being a Carer. I am interested in your own personal experience which may be different from other people's, so tell me what it has been like for you. I would like to record the conversation with your permission. We will be able to arrange an opportunity for you to hear the recording if you would like. Should you wish to stop the interview at any time, or take a break, please tell me. Because the topic of our discussions is sensitive I can assure you that it will remain confidential.

Section A

NOTE: Ongoing homecare/Since bereaved/Since institutionalised/Periodic Respite.

1. I would firstly like to **recap the key things** that we talked about during our last interview (before/after diagnosis and at time of last interview).

Prompt: Anything I missed? Anything you'd like to add? Anything I got wrong?

Section B

I would now like to ask you about **the general changes since our last interview** in light of the recap.

2a. Changes in spouse's health

2b. Changes in your own health

2c. Changes in support (refer to diagram, or see below)

2d. Any other significant events, e.g. respite, birthday party, wedding anniversary.

2e. Do you think you've learned to cope better? More resilient?

Ask participant to fill in a copy of the first support diagram.

I'd like to ask about the various kinds of support you receive at different stages.

Prompts: Informal, e.g. Friends, family, neighbours. Formal, e.g. Support workers/CPN/Doctors.

Section C

I would like to ask you to think about what it is like now?

3a. How do you spend your typical day? (<u>on own - if at all - and with husband/wife</u>)

Prompts: what about the household chores?

do you see or go out with family or friends?

how do you get around? Public transport, cash etc

do you have people you would consider true friends?

<u>Would you say that you do anything new at all?</u>

3b. How do you feel about that? (and generally)

Prompts: how are you?

what is your mood like?

do you feel better/worse/or the same?

how are you with other people?

can you tell me more?

3c. What is your relationship like now from last time?

Prompts: Better/worse? Do you disagree more/less?

3d. Thinking about your roles and responsibilities in the family, <u>what are they now, and how have they changed since last time?</u>

Prompt: What do you do for your husband/wife?

Would you say you have assumed more responsibilities?

Cooking, cleaning

Housework

Home maintenance

Finance

Car

3e. Are the kinds of support you receive different now than they were last time?

Prompt: Anyone new? Do they help out too?

<u>Ask participant to fill in a copy of the second support diagram. Compare.</u>

3f. What has changed <u>most</u> since our first interview?

Prompt: Can you tell me more?

Did you say (?)

In what way.....

4. Some people become particularly successful at being a carer and we are trying to understand how.

People say that caring becomes easier over time. Has this been the case since our last interview?

Was there a particular occasion, since our last interview, which you could say was a 'turning point', after which being a Carer became easier?

Or was it a gradual process?

Or maybe there were a series of smaller but identifiable steps which led to life being easier?

Which people, or perhaps events or places, remain helpful? (e.g. support groups?)

You might want to ask if there is something that has made it harder

5. Is there anything else you would like to talk about at this stage?

Anything I forgot to ask?

Things you think I should be asking about?

Things you wouldn't say in the group? (personal, intimate)

How should I ask these questions?

Section D

I would now like to return to our earlier interview and ask you some more general questions.

6a. What would make life easier for you at present?

6b. Is there anything that you've learnt since our last interview that you'd give as advice to someone in the same situation as yourself?

Appendix 10

Time 2 former carer (institutionalised) interview schedule

Spousal Schedule – T2 Since Institutionalised

The development of resilience among spousal caregivers:

Thank you for agreeing to talk about your experience of being a Carer. I am interested in your own personal experience which may be different from other people's, so tell me what it has been like for you. I would like to record the conversation with your permission. We will be able to arrange an opportunity for you to hear the recording if you would like. Should you wish to stop the interview at any time, or take a break, please tell me. Because the topic of our discussions is sensitive I can assure you that it will remain confidential.

Section A

NOTE: Ongoing homecare/Since bereaved/Since institutionalised/Periodic Respite.

1a. For how many years were you caring for your spouse until they went into care?

Section B

2a. I would firstly like to **recap the key things** that we talked about during our last interview (before/after diagnosis and at time of last interview).

Prompt: Anything I missed? Anything you'd like to add? Anything I got wrong?

As part of this recap, ask participant to fill in a copy of the first support diagram.

I'd like to ask about the various kinds of support you receive at different stages.

Prompts: Informal, e.g. Friends, family, neighbours. Formal, e.g. Support workers/CPN/Doctors.

Section C

I would now like to ask you to think about the build up to him/her going into care. I know this might be painful, so we can take it slowly and we can stop if you like.

3a. Can you tell me what happened?

Prompts: Was it unexpected?

How did you care for them?

Who helped you?

3b. Who made the decision to put spouse into care?

Prompts: Was it a medical decision or a personal decision?

Why did you/they decide?

What prompted the decision?

Who helped you make it?

Was there any disagreement?

How did it make you feel?

3c. How would you have described yourself to me if I'd met you then?

Section C

I would now like to ask you to think about the weeks immediately after him going into care. Again I know this might be painful, so we can take it slowly and we can stop if you like.

4a. What did you do?

Prompts: what did you do during the days following?

did you go out?

what did you do on a typical day?

did you see people?

family support?

How often did you go to see him/her

Other social support?

4b. How did you feel?

Prompts: how were you?

What was your mood like?

What happened as the days passed?

How were your thoughts?
Did your feelings change?

4d. How did you feel after some time had passed?

Prompts: How were you?

What was your mood like?

Did you feel good or bad?

How were your thoughts?

4e. How were you with other people? (refer to support diagram)

Prompts: Who did you surround yourself with?
Had your social life changed?

Who would you have turned to for someone to talk to?

Why?

Section D

I would like to ask you to think about what it is like now?

5a. How do you spend your typical day?

Prompts: Do you go to visit your spouse?

what about the household chores?

do you see or go out with family or friends?

how do you get around? Public transport, cash etc

do you have people you would consider true friends?

Would you say that you do anything new at all?

5b. How do you feel about that? (and generally)

Prompts: Did you feel good or bad?

How are you?

What is your mood like?

Do you feel better/worse/or the same?

How are you with other people?

Can you tell me more?

5c. Thinking about your roles and responsibilities in the family, <u>what are they now, and how have they changed since last time?</u>

Prompt: How are they different from being a carer?

Would you say you have assumed more responsibilities?

Cooking, cleaning

Housework

Home maintenance

Finance

Car

5d. People talk about the way in which they begin to see themselves differently, as they are making changes practically to their lives.

Prompt: How do you feel about this?

How do others see you?

5e. Are the kinds of support you receive different now than they were last time?

Prompt: Anyone new? Do they help out too?

<u>Ask participant to fill in a copy of the second support diagram. Compare.</u>

5f. What has changed <u>most</u> since our first interview? (other than spouse going into care)

Prompt: Can you tell me more?

Did you say (?)

In what way.....

6. Some people say that caring becomes easier over time.

Do you agree, now that you've got that respite?

Was there a particular occasion, since our last interview, which you could say was a 'turning point', after which being a Carer became easier?

Or was it a gradual process?

Or maybe there were a series of smaller but identifiable steps which led to life being easier?

Which people, or perhaps events or places, remain helpful? (e.g. support groups?)

7. Is there anything else you would like to talk about at this stage?

Other significant changes since our last interview other than spouse's institutionalisation, e.g. your health, birthdays, anniversaries?

Anything I forgot to ask?

Things you think I should be asking about?

Things you wouldn't say in the group? (personal, intimate)

How should I ask these questions?

Section E

I would now like to return to our earlier interview and ask you some more general questions.

8a. What would make life easier for you at present?

8b. Is there anything that you've learnt since our last interview that you'd give as advice to someone in the same situation as yourself?

Do you think you've learned to cope better? More resilient?

Appendix 11

Time 2 former carer (widowed) interview schedule

Spousal Schedule – T2 Since bereaved

The development of resilience among spousal caregivers:

Thank you for agreeing to talk about your experience of being a Carer. I am interested in your own personal experience which may be different from other people's, so tell me what it has been like for you. I would like to record the conversation with your permission. We will be able to arrange an opportunity for you to hear the recording if you would like. Should you wish to stop the interview at any time, or take a break, please tell me. Because the topic of our discussions is sensitive I can assure you that it will remain confidential.

Section A

NOTE: Ongoing homecare/Since bereaved/Since institutionalised/Periodic Respite.

1a. For how many years were you married up until your spouse died?

1b. How long have you been widowed?

1c. For how many years were you caring for your spouse until (s)he died?

Section B

2a. I would firstly like to **recap the key things** that we talked about during our last interview (before/after diagnosis and at time of last interview).

Prompt: Anything I missed? Anything you'd like to add? Anything I got wrong?

As part of this recap, ask participant to fill in a copy of the first support diagram.

I'd like to ask about the various kinds of support you receive at different stages.

Prompts: Informal, e.g. Friends, family, neighbours. Formal, e.g. Support workers/CPN/Doctors.

Section C

I would now like to ask you to think about the weeks before s/he died. I know this might be painful, so we can take it slowly and we can stop if you like.

3a. Can you tell me what happened?

Prompts: Was it unexpected?

How did you care for them?

Who helped you?

Section D

I would now like to ask you to think about the weeks after s/he died. Again I know this might be painful, so we can take it slowly and we can stop if you like.

4a. What did you do?

Prompts: what did you do during the days following your loss?

did you go out?

what did you do on a typical day?

did you see people?

family support?

Other social support?

4b. How did you feel?

Prompts: how were you?

what was your mood like?

what happened as the days passed?

how were you with other people?

did you feel the presence of your husband?

what was your memory like?

how were your thoughts?

4c. How would you have described yourself to me if I'd met you then?

4d. How did you feel after some time had passed?

How were you?

What was your mood like?

Did you feel good or bad?

Did you feel the presence of your spouse?

How were your thoughts?

Did you have dreams?

4e. How were you with other people?

Who did you surround yourself with?

Had your social life changed?

Who would you have turned to for someone to talk to? Why?

Section E

I would like to ask you to think about what it is like now?

5a. How do you spend your typical day?

Prompts: what about the household chores?

do you see or go out with family or friends?

how do you get around? Public transport, cash etc

do you have people you would consider true friends?

Would you say that you do anything new at all?

5b. How do you feel about that? (and generally)

Prompts: Did you feel good or bad?

how are you?

what is your mood like?

do you feel better/worse/or the same?

how are you with other people?

can you tell me more?

5c. Thinking about your roles and responsibilities in the family, what are they now, and how have they changed since last time?

Prompt: How are they different from being a carer?

Would you say you have assumed more responsibilities?

Cooking, cleaning

Housework

Home maintenance

Finance

5d. People talk about the way in which they begin to see themselves differently, as they are making changes practically to their lives,

Prompt: How do you feel about this?

How do others see you?

5e. Are the kinds of support you receive different now than they were last time?

Prompt: anyone new? Do they help out too?

Ask participant to fill in a copy of the second support diagram. Compare.

5f. What has changed most since our first interview? (other than spouse's death)

Prompt: Can you tell me more?

Did you say (?)

In what way.....

6. Some people say that 'time heals'.

Do you think that 'time heals' in widowhood? When caring?

Was there a particular occasion, since our last interview, which you could say was a 'turning point', after which being a Carer/Widow(er) became easier?

Or was it a gradual process?

Or maybe there were a series of smaller but identifiable steps which led to life being easier?

Which people, or perhaps events or places, remain helpful? (e.g. support groups?)

7. Is there anything else you would like to talk about at this stage?

Other significant changes since our last interview other than spouse's death, e.g. your health, birthdays, anniversaries?

Anything I forgot to ask?

Things you think I should be asking about?

Things you wouldn't say in the group? (personal, intimate)

How should I ask these questions?

Section F

I would now like to return to our earlier interview and ask you some more general questions.

8a. What would make life easier for you at present?

8b. Is there anything that you've learnt since our last interview that you'd give as advice to someone in the same situation as yourself?

Prompt: Do you think you've learned to cope better? More resilient?

Appendix 12

Coded time 1 transcript (Mr Go.)

Okay so I'd first like to start by asking you half a dozen factual questions ok so you care for your wife ongoing at home

I look after my wife [wife] yes at home yes

Right but first can I just take your surname

My surname's [Mr Go.] and my first name's [Mr Go.]

Right okay and what's your data of birth

It's the 19th of May 38

Okay and where were you born

I was born Whiston Merseyside

Okay how long have you been married

Erm 52 years

Okay and how long have you been caring for your wife

I would say maybe 10

Okay do you have any children

I have a son and a daughter the daughter lives away and the son lives locally where I live my son visits three or four times a week from work

Right okay and do you have any grandchildren

Yes I have grandchildren three grandchildren and two great grandchildren

Right and can I just ask what your job was

My job it was a joiner

And what was your wife's job

My job was she was in the clerical accounts accountancy

Right brilliant that's that bit done. So id now like to ask you about before any problems started so your married life basically before any issues

Well I met my wife when she was seventeen and erm probably the only girl I've been with really and erm we were married when she was twenty and I was twenty two and erm as you know we've been together ever since and situation is that we've always done things together erm like an ordinary family arguments have been there and you work through things bringing up two children everything mortgage and er she did her thing and I did my thing and we gelled together Together

It worked

It worked absolute worked but again she was more a dominant one took decisions erm pretty well about everything actually. I mean for forty years I've had such an easy life but put it this way I've learnt off her over the years so I have learnt off her as far as my wages were always paid into the bank and she always looked after the money situation and I think everything with the marriage is trust and we trusted each other so there you go and she bought everything and many things she bought was in her name anyway but it didn't really matter to me really it's just that she was buying them and in her name so the situation it just grew and grew if she was making the bed for instance, she'd say to me because she was working and things she'd say putting a duvet on and things give me a hand and Marital roles

over a period of years we learnt to do things because you work together. Not that we were in each other's pockets, we weren't, I used to do my thing and she used to do hers but erm when about ten years ago really I noticed she used to always write letters, never used a computer I mean we did go for letters should have kept it up like everything else but we didn't keep it up but she used to write the letters by hand but really I first noticed when she used to get the dictionary out and looking at words cause normally she'd do a letter in half an hour no problem. Words she'd just roll off, write the words, but I noticed she started going to the dictionary more for spelling and things like that and er another thing in the kitchen things were getting put in places where erm they'd normally don't they're not there they shouldn't be there and I'm going for milk and it's in the cupboard or something like that. So one particular time I used to take her to the doctors if she needed to and wait outside or whatever or the hairdressers and as I say we were always together because I used to work kind of maybe seven days a week half day off Saturday and I used to work a lot and my wife used to say to me be home for half day Saturday whereas me mates used to have a drink and things like that I used to go and have a drink with them but then I knew get back home for my wife because she'd want to go shopping and I used to say why do you want me to go shopping with you all the time. She'd say well you're working which I was working Saturday and Sunday and we never really got out.

Work together

Slight deterioration

Together

Work

Mates socialising

Work

Yeah

I was tired with working and everything we never really got out so she said we'd go shops we'd go into Liverpool which we did and then on the way home we'd go for a meal. Believe it or not that was for a period of few years. That was us going out together and erm I used to say well I'll have to keep on working because you

Together

never know when it's going to stop. You can't foresee the future or anything like that.

You can't see it

That's what happened actually

We'll talk more about that in a bit. So what would you say your married life was like then.

I would say my married life was brilliant and I know the situation as she is now and as I said we'd go to the doctors this particular time she was going to the doctor's I happened to go in with her and you hear all kind of stories about doctors putting patients off and telling them to come back but this particular time I just happened to mention about her memory nothing to do with me really I suppose she gave me a really bad look

Good marriage

First suspicions

(laughs)

But he kind of tested her there and then and the next thing the balls were rolling because he wrote a letter to the hospital and she got diagnosed very early and that's why as I say ten years but it's been a very very slow process over them ten years and I must admit erm even now she can't do anything at all now. She's full incontinent and everything. I do everything but erm she's very good she's always laughing when I met her she was laughing and that's one thing

Quick diagnosis

Slow process

Fully dependent

Laughing

Some things don't change

And she still laughs now and honestly it makes my day and I sing and I do all kinds and she's laughing. I'm happy I am happy I'm not just saying it and things are not

Laughter/happy

on top of me at the moment. What they'll be like when I get older maybe in six or seven years' time I've no idea but you take every day as it comes

Is that how you work it

Yeah. And it's good. I go to the carer's I go to the Alzheimer's I'm in the Alzheimer's society which is it's in the reformed church in St Helens and I come here, the Kershaw, my wife comes to the Kershaw twice a week and erm everything ticks over alright its fine

Carer support groups

Ok I've got something I need to

I tell you what I've never stopped have I. Have I been talking too quick have I

Not at all. What I have here is a little thing it gets you to think about throughout your married life before any of these memory problems started I want you to think about people who were in your life in a typical week so before anything went wrong but on a common kind of week what kinds of people who would you come into contact with so your work friends I presume.

Well actually typical week well at the moment the day off I go on a computer course so I go to a computer course which is run by the library which and I go there and erm I've always kept myself busy if not doing messages come in contact I go to the carers centre a lot I've done all the courses there at the carers centre in St Helens but every week is different really

Keeping busy

Just a typical week you know perhaps people you see

Well people I see I see my sister my brother lives in Rainford my brother is eight years older than myself he never got married my sister lives in Southport my son comes about erm comes about three or four times a week from work

Siblings

Son

So quite regular

He does yes erm and I go what would you put down for computer course

Erm just write that and I'll know what you mean cause if you go there every week that's something else isn't it

Computer course erm and really I like I like actually pottering round when the weather was good in the garden and things like that but I see the neighbours as well really a lot and also I went to see one chap who's like my wife with dementia he just go into hospital I went to see his wife yesterday and she's one of the neighbour she lives locally how can I put that erm I talk to neighbours as well I even have tea with them as well

Neighbours

Brilliant and do you know the person you went seeing in hospital

I didn't see him in hospital I actually went to see his wife he's in hospital and I went to see his wife she's at home just to see how he is

What's the matter with him

He wasn't as bad as my wife really and he suddenly got this stroke and he's gone into hospital believe it or not he's just gone downhill since he's gone into hospital whatever the cause of all that is I've no idea its absolutely frightening really it's the most frightening I have I can I've done everything else I know how to handle it but this going into hospital is another thing and I have got a record of when my wife gets up in the morning what she eats and I've got it all in a record book her day what happens in the day toilet and what happens in meals and what happens on a night time so if anything did happen I would hand it to the sister or somebody in the hospital

Frightening

Organised

Right so you've got a record

I've got a record of all that through one of the carers they give you a book which is my life on it and my wife's actually wrote everything down on that

That'll be a big help because I think it's very particular

I do think the hospitals I mean even on the news this morning again dementia is coming up more and more people are being aware of dementia the government has just brought something out now about people being more aware of it people who you work with they reckon 1 in 3 people over 60 will get dementia at some time in their life and they're asking people to be more aware of it people they work with just because catching it early can help and I think in the future it may help an awful lot

Government

I can imagine so yeah definitely so that's a typical week anyone less frequently who you see

I see my daughter rarely

Daughter

How often do you see your daughter

Maybe every few months

Right ok anybody else like that

Well the granddaughters they live round where she lives and some live in Birmingham it could be the same really you know. Mind you the other week they've just erm passed their test and they came to visit us so maybe it's just the start cause my wife used to kind of when they lived in Rainford cause actually we gave my son so much towards a house when they first got married and they lived the daughter lived in Rainford where I live and the grandchildren growing up

Grandchildren

three of them when they was small we used to look after them all over the weekend and take them out and take them on holiday and everything so a lot of this is in the memory of the childhood but of course they're 20 21 I don't think anybody that age understands dementia really what it's all about

Don't understand

Until you've gone through it for years and years right so is there anybody else less frequently that you see less frequently than a week for example

Let's see erm

Doesn't have to be family it can be other friends or distant relatives

Erm I'll just put friends down is that alright how many friends should I put

Just other friends that you see

Friends of my wife

Ok and what about the staff here that's every month here isn't it but you go to other groups as well don't you

I do yes and that's every week that's the Alzheimer's isn't it and there's lots of friends

Friends

So there's friends in there as well

Yeah lots and its very good because they accept you more don't they I mean the friends you have they suddenly when you think about all the friends you used to have they don't ask you to visit anymore

Friends drop out

So they can relate

That's the sad thing erm

It's the one in the town centre isn't it okie doke

This one carer's centre Kershaw erm what else can you put that's

Any people you come into contact with just a different way of thinking about it isn't it

I know I know I know

We can come back to it

Yes we might think of something else

Ok we'll put that there I'd now like to ask you about you mentioned before around the time you first started noticing things so kind of leading up to this doctor when he did that test what else how did you get there when you went to the doctors what was the turn of events that led you to going to see the doctor about it

Well as I say before erm I took my wife to the doctors and the doctors are both they're in Rainford the practice is in Rainford where we live and I just happened to say do you want me to come in with you and she just said this particular time and erm as doctors are you can just talk openly to them and it kind of just come out like you would do at any time just say well I think your memory is going a little bit bad just like that through conversation a lot of people would just go onto something else kind of thing but the doctor picked it up and erm just off the cuff he said he put about four or five objects down on the table and he said to my wife just remember them and of course I was looking at them myself and he said I'll ask you to name them in a couple of minutes (laughs) I was getting all worried myself

Memory test

(Laughs)

But anyway whatever she did he must've thought well I'll do something about it he could have just left it I mean there was nothing drastically really I would say really bad or anything like that

Thinking back do you appreciate that he was quite fast

Well what I appreciate is first of all the memory loss could be all kinds of things and when the hospital did see the consultant it was they checked her blood her heart right through scans and everything to see if its pumping to the brain and then last of all they gave her a brain scan you see and then it came up with vascular dementia of course it threw me I didn't even know what vascular dementia was really Alzheimer's there's that many forms of Alzheimer's I was kind of relieved when he said it wasn't Alzheimer's so really when you know now everything's pretty well the same

Diagnosis

Relieved

How did you feel when you were told that when you realised what it was

To me it didn't really hit me erm very hard or anything really it wasn't I wouldn't I would think now I know Alzheimer's if someone says you've got Alzheimer's they know they're kind of in sound mind they know all the what happens with Alzheimer's they know what the future holds if somebody says to you the doctor that you've got Alzheimer's but with vascular dementia I knew my wife she not once she never once said there was something happening to her she never said she was losing her memory she never said she can't do this or cook and she never done that she never said and to this day she's never said anything and I thought to myself maybe vascular Alzheimer's you know you've got something that's wrong with you that's progressively gonna get worse and you know that and you can tell

Reaction

Insight

people you've got that you see but with vascular especially with my wife she's never once said there was anything wrong with her so she's lived for ten years and steadily got not complaining she's never moaned she's never complained in her life about her situations. In fact as I said to you before she was the strong one the positive one and as a man you always have your moans and groans she was used to tell me to get on with it come on get on with it, see. And the thing is with her she's never complained and life is so rosy she trusts me and she lets me do things like at first it was a struggle because she used to say it's not your job to iron it's my job to iron cause I never used to do any ironing I'd never ironed in my life I've never washed anything in my life see but I've seen how it was done you see so the whole thing is when I first starting I was doing a bit of ironing cause I found putting in the steam kettle she was putting she was pouring the kettle and putting the hot water out of the kettle into the iron see instead of just putting it in the jug it worried me a little bit and things started about the iron so that's when I started doing the ironing and she said your job is outside the garden and doing pots but over the period of time I've got into all this

Wife positive

Change in gender roles

So what else not just now but when it first came about what else would you start doing that you wouldn't normally do

Well when we went on holiday I'd never packed a suitcase she used to buy my clothes mind you I used to go with her she used to say do you like that or if she was out on her own she'd see a shirt and she'd say oh [Mr Go.] will like that shirt and sure enough she had some taste where I had no taste (laugh) I've no taste but then it got thrown to me it's a different ball game when you've got to do it yourself I mean I used to go we used to have friends and he was more he knew his wife's dress sizes and my wife used to say what was I wearing for the party we

went to last week and I couldn't really remember and you're not observant are you but he would he'd remember that but this is the thing now what's happened now over the years I've got more and more confident I've done things which I've never done in my life I can buy things with confidence I know my wife's sizes all her sizes I remember what she was wearing yesterday last week or whatever because I'm doing it and really I wish in a roundabout way that I'd have been more observant and more like this years ago but then I thought to myself she didn't really let me do it she wanted to do it

Change in gender roles/confidence

That's hindsight isn't it

But she wants to do it at all and if you meet somebody warren who wants to do it you just roll along and it's a good life I mean my wife believe it or not used to do decorating and the thing is when we first got married I'd never decorated in my life and my wife was a perfectionist she was a perfectionist she'd go out and say I'll start this wallpapering I'll never forget it in our first house and I was doing the chimney breast quite pleased with myself I just put the wallpaper up and when she came in she looked at it and she said that's not straight and I said well alright what about friends when they come I said well don't worry just tell them [Mr Go.'s] done it. I can't have that and it used to go on in the end I mean don't get me wrong I'm stubborn as anything and I turned round and said if you take that wallpaper off I won't do any more wallpapering and it got a little bit of a friction

Stubborn

What happened

She took it all off I walked out I mean it wasn't for very long but I walked out she came back took it all off and did it properly really good but from that day to this I never done any wallpapering but she never argued she never pulled me up and

said you're this that and the other she used to enjoy doing it and all my friends used to say you're lucky you are but that's another thing Warren three or four years ago of course the house we lived in we live in a bungalow she picked a bungalow and it's the best thing she ever did in her life it's a three bedroom bungalow so the children it was good and it's a blessing now so the rooms started needing wallpapering and I'd never wallpapered in my life and how old 69 70 doing wallpapering you'd never believe it would you I went and picked the wallpaper whereas normally there's two of you to choose wallpaper I done it myself went and picked it up from B&Q and whilst she's been here coming to the Kershaw I've always been a slow sort of person and she'd go out and come back when I've done a job and she'd say are you still doing that job cause I've taken my time I've always been slow I've never rushed and er over a period of a few weeks I'd wallpapered the whole room done the ceiling I was quite pleased with myself I was telling everybody they must've thought I was mad honestly

Moved house

New role/confidence

(Laughs) and you'd not done it for years and years

I've never done it in my life and of course it's a shame because I'd done it properly as well it was good because I'd watched the way she's done it especially the corners and around the sockets and things I used to watch and I'd just done it and I'd done it properly and of course the thing is she comes home and you can say this doesn't make any difference but that's nothing it's what it does for me really and that's another thing I've done in my life

And it's quite funny as well when you look back to the time when she ripped it all down

Oh God but really she was never the one to pull me up on that cause she quite liked doing it she loved doing the wallpapering and things and jobs like if she wanted me to do a job in the house a joinery job I'd just say to her erm draw me a plan draw me a map and she'd do it all and I'd do it to that you see so it was exact she was good for me I'm quite happy I'm really happy honestly

Good relationship

Brilliant so thinking about now then in light of what we just said you mentioned that's kind of helped now cause she's always been

Yeah there's a lady there that gets the bus with (wife) and she's hard to get off the bus now but it's just a phase probably she's going through and things like that but I work round that and I sit and wait our bedroom is on the front actually and of course the dark nights now and I'm sitting and waiting for the bus to come its various times could come at quarter to 5 or half past and soon as it pulls up I shoot out and I always there's cups of tea I say to her she gets up for me really I feel for the people who help her off they shouldn't have to try and get her off if I'm there she gets off for me she's good

Transport

Empathy

Right so how do you spend a typical day now then

Well really we used to get the bus she used to like going on the bus or the train and I find it quite hard now with the circumstances there was a bus at one time going to Southport and erm it used to go from Rainford come through St Helens Rainford straight to Southport you see but this was about two years ago but for some reason when we got to Rainford she wouldn't get off and you can't force them so we ended up going to St Helens

Difficulty travelling

(laughs)

But that was no problem

Just adapting to it

So we go in the car now and we're out pretty much every day I get out every day erm and we get back in the afternoon and I feel if we're out in the morning cause erm and back in the afternoon she's better she's getting a bit tired she's alright but to keep her in the house all day and it's no good for myself being in all day

Keeping busy

So for both of you

Even if we just go out and we go we don't have to go round the shops all the time we can go places and just go for a walk or Southport go into Liverpool go we park the car up in Liverpool and erm there was a bus actually no we went by train this was the other week we happened to go by train parked the car at the station went by train and then there was a bus that took you round to the Albert Dock cause I thought being quite a walk to get to the Albert Dock so we got this bus that stops in the Albert Dock so we spent quite a few hours round there the only thing I find difficult now really and I find going on my own is when we go for coffee and things like that because when it's quite crowded when you go into these places and I'm carrying bags I carry everything if there's a tray if there's tea couple of scones or something I can't put her at a table cause she's liable to get up its very very hard and we do go once a week to Marks at Gemini

Out and about

Difficult

Oh yeah

And we go there and we'll do a bit of shopping get some of the food there and we do a bit of shopping there because I must admit in Marks they help you I mean sizes for instance if I want any information I'm not too erm shy to ask anybody now I'll ask anybody can you help me and people will fall over backwards to help you and the assistants have taken me all around that store and helped me with

Shop assistance

clothes for my wife different types of clothes which I've bought and when we go in the restaurant low and behold there's a young lady there and she just says sit down and I'll bring you whatever you want even if its crowded which is absolutely brilliant for me and in fact when she first started doing it there's signs now with my wife she kind of stoops a little bit now she never used to do that and she never she was always a very quiet person with this dementia she wasn't very loud and very quiet she just doesn't talk or anything and the thing is and the thing is people didn't know she had it cause I must admit she looks quite good and she wouldn't but now the tell-tale signs must be there with me holding her hand and being more protective than I was before and she picked up on this (shop assistant) when we first started going and she realised and from then on she's brought us our tea and whatever we want and I did go to the superintendent the manageress and I just said thank you very much because erm I always thank people I always do and I thank them because its brilliant I really do and there's so many people who are very very good honestly I mean I can go right through and talk about them all I mean another thing that went through my mind was the dentist as I've put down on the paper there the dentist we had one in St Helens where we used to go every six months and then about 18 months ago (wife) went sat in the chair and just wouldn't open her mouth wouldn't open her mouth I asked the dentist different things and erm she couldn't do anything she says well so that was another worry but I've managed to find people that would help me to find someone which there was in St Helens a dentist which is a national health service dentist and she happened to go there because had to be referred from the practice we were in now I'm still in that practice and she got referred and erm is it it's in College Street actually first of all he wanted to check her mouth and he was absolutely brilliant I

Signs of deterioration

Thankful

Happy with wife's health care

must admit and she'd been twice and she's kept kept her on his books so I was over the moon with that

Bet you were so all these things have helped haven't they

I did ask him if anything happened in the future what would happen and he said we'll sort that out I can do all that so that's another way of looking at it isn't it

So you're happy now then

I'm happy with that I'm happy I'm very happy — Happy

And what's your relationship like now

Absolutely brilliant brilliant it is I couldn't I come here every month and people open up as you know different people open up and I go away feeling how they are and what they've got to put up with and what with their husbands or wives or whoever they've got to look after and some of them are older than me and god forbid my heart goes out for them I mean I'm lucky because

Brilliant relationship

Downward comparison

Makes you feel fortunate

Yeah at this moment in time but god forbid I'm able to do it

What do you have that they don't

I don't know I have erm I'm very positive I'm not saying they're not positive by any means I'm just telling you what I've got and the thing is I don't know what they haven't got but I'm positive I laugh and I sing and she laughs and I act soft in the house erm if anybody came in and listened to me I've even said to one of the neighbours about my singing and she says John it's a good job we've got a detached house I sing at the top of my voice yeah

Both positive

Make the most of it

I don't know what the future holds but for forty years Warren I've had it good haven't I it's my turn to do a little bit really isn't it it really is — Thankful

You can look at it like that can't you

I definitely look at it like that and I know one thing Warren I know one thing she'd do the same for me oh God she would (upset) — Mutual care

Yeah

She would

Does that put your mind at rest

It does it does honestly I'm happy I'm happy — Happy

Best way to be isn't it if you can

Yeah what else do you wanna ask me Warren

You've been brilliant I like it when people talk cause I don't have to do anything

Well I never stop because the thing is Warren at home I'm just talking to myself I talk and I have a voice like (wife) I make a voice with (wife) if I ask her does she want a cup of tea and then of course she doesn't answer me so the next thing I'm saying yes please — Humour

(laugh)

And hurry up I'm saying come on hurry up so then I say oh don't shout at me (wife) don't shout at me and then she's laughing she puts her head up like she — Humour

used to do like kind of I'm going and that's how she used to do throw her head back — Maintaining continuity

It's funny

Oh God so of her mannerisms are still there really I mean she looks at me sometimes you know her head goes like that as if to say what's he doing there but — Maintaining continuity

erm I mean when we go to bed as well really I mean I do everything I undress her and we do it really and erm the bedroom is at the front or we're in the lounge you get undressed there — Personal care

and erm I always tuck her in and I stroke her head and everything and she's made up going to bed and its good — Intimacy

I bet that's helpful as well cause some people say it's a nightmare getting them in bed

Well that's the way I do it because erm I tuck her in of course its hot water bottles now I mean I'd love to leave the hot water bottle in her bed sometimes but you can't do that really and I tuck her in and the best thing really I mean we did have an incontinence nurse coming here to the (day care centre) again another service being very very helpful for me very helpful and now (wife) will sleep right through the night she sleeps right through the night I don't get her up or anything but in the same token erm she's awake around 7 o'clock now you could I'm always up early with going to work I'm up at quarter past 6 I can't sleep but I don't really feel I must have had enough sleep cause I don't feel really tired and at seven I get her up I get her up and it always takes time to get her ready but I put her dressing gown on first and then she has her breakfast which I've got things sorted she's — Routine

So you know what's coming and when

Yeah and erm as I say it takes her a couple of hours get a shower and whatever and go into the bathroom takes her a couple of hours we wanna get out for half 9 getting ready for about we start getting ready for about quarter past 8 so then we're out the house for about half 9 quarter to 10 quite early and all the blinds are still shut because there's a lot of old I'm old now really but you always think other people are older and they must think about us getting up and getting out I like getting out early and erm it suits her as well

Getting out

Is there anyone you can think of who is perhaps in your life now who has come about because of this other than the staff here people like that who wouldn't have been in your life without you know

Well there's loads people in the Alzheimer's there's lots of people who are there and they're not all if ever I need help or someone to talk to erm I've got them to talk to there's loads of people there is people out there

Carer support workers

Right and what about you touched on your son who comes four times a week

My son comes from work cause as I say he's got his own house in Rainford he comes from work he's got a partner he's not married and he's got no children he's 44 now and erm he's great absolutely great but he with a son its different and I don't say they don't care as much as a daughter but they're not as hands on as a daughter could be a daughter knows her mother a daughter could take over lots and lots of things and help me more and I suppose here in the (day care centre) and the carer's there's people who have daughters who do help them but my son he's he misses he used to have he's the same as my wife my son he's a bit of a perfectionist and he's the one years ago who used to have the arguments where I used to be the middle of the road she used to tell and his mother if he asked his

Son

Son/daughter roles

mother how he looked or or anything at all she'd tell him straight what she thought and although at times it may be hurt I wouldn't be like that I don't know it's the way you are I would kind of she'd tell him the truth but you'd know where to go to if you wanted the truth how he looked because if he asked me how he looks to go out I'd say oh you look great you look alright but erm he may not do

Family roles

(laughs)

But with my wife he'd know that if it was alright she'd say it's alright if it wasn't

She'd tell him

He'd have his arguments and he said to me one time one thing I miss Dad is the stimulation I get the stimulation through her cause at the end of the day they always put their arms around each other which they do and that's another thing which my wife has done for me she's made me a loving person in lots of ways maybe it's been inside me I don't know but my family never kissed anybody my sister when you used to go to my sister she'd turn her face away my family weren't a caring because circumstances they weren't close my mother rarely although they did a lot for me don't get me wrong you love your mother to bits but my mother never said I love you John but that's the way they were in them days but (wife's) family were different when I met (wife's) family she used to have arguments with her Dad but it was strange because before we left they'd all have their arms around each other kissing each other and I thought what am I getting into here

Stimulation

More loving/affectionate

(laughs)

And over the years

Its drawn it out of you

I've done the same and honestly I kiss people I put my arms around them I never used to do that that's (wife) that that's my wife who's done that for me — Affectionate

So that's changed that do you think you've always had it inside you

I don't know but even here I've noticed and sometimes I think I shouldn't do it even the ladies here I just give them a kiss look after yourself it's something which they always did my wife's family did they were a caring family honestly and of course even my own brother now I've got him and my sister I throw my arms around him now and give him a kiss my own brother and I think — Sibling affection

It's a nice thing isn't it

Well he was a little bit when I first really but you know the way you are isn't it that's the way you are

Exactly it's a nice change

Watch yourself Warren before we go out

We'll save it for when I press stop (laughs) so what would you say has changed the most then from the start right through to now I know you mentioned you're happy and that's great

Changed for me I'm more positive I've got more confident I can do things I'd never done before in my life and you know at my age now I'm being able to do all them things it's probably always been in me to do these things but they've all come out because I've had to do them and I do believe everybody if they put their minds to it and they have to do something erm and they love like I love my wife I love her to bits and I keep telling her I love her and the love there you have you'll do — Positive/acquired skills — Love

anything you'll do anything and it's like yourself if you're really interested in doing it and you want to do it nothing will stop you you'll get anywhere you really will get anywhere education I always think because my mother and my father married brother and sister erm my mother married my father's brother and my father's sister and what happened is her brother ended up from the same family and everything the brother ended up a sea captain they ended up middle class living in Chester the sons went to University teachers lecturers clever and everything our family were the poor family although it was my mother and I always said it's in our genes isn't it we've got the same genes as them we must have mustn't we and why aren't we it's just in us we didn't have the opportunity did we we didn't really have my father died when I was only about 11 mother had 3 jobs and erm you just had to left school at 15 and nobody homework no one checked no one had any homework but education it was there I know it's a bit late in the day now but I've really come out now I really have and it's all part and parcel of the way (wife) is I mean I don't get me wrong I'd rather have her back to the way she was I don't know I have learned a lot really

Resolute

You've learned a lot and you've changed in a good way perhaps you wouldn't have changed if things had stayed the same

Well if she'd have carried on doing everything I mean

Might have been you

(laughs)

Might have been the other way round might it

I've never stopped I'm sorry

No last little bit anyway some people say that you can become quite a successful carer you do a good job of it in other words and that perhaps over time you learn to do better and you learn from your mistakes and stuff what do you think

You do learn from your mistakes and the mistakes you make at first when you first go along I mean you get upset and you do raise your voice and don't get me wrong I was never a push over even in all my years I was stubborn as anything we used to have our arguments that was my fault I suppose and the thing is I'll say this quickly cause we haven't got much time have we erm the whole thing is is I used to couldn't understand why (wife) did things and it used to annoy me that she was doing these things and not knowing the full circumstances whilst she was doing them and I used to shout and things like that but as it progressed and the shouted started easing up and what are you doing that for and things erm if I ever did it erm afterwards after a while I started feeling all this remorse and erm horrible feeling because I hadn't realised the situation she is but its leading up to that really and erm the way I see it now she just doesn't know really like erm you don't realise how she thinks you've got to try and get into her head really how she thinks and why she does these things

Mistakes

Remorse

Empathy

Yeah so its learning not to perhaps pull her up and try to understand it

Well you don't pull her up you can pull her up but you don't pull her up in you pull her up in a gentle way and you talk when somebody if they lose their temper erm they raise their voice and things you always keep your voice quiet she used to always say to me my wife if you wanna win an argument at anything talk normal talk quietly the quieter you are the better half wanna win it people who always lose an argument are people who start raising their voices I could never learn that but I've learnt it now that's what I've learnt

Gentle

Exactly

Just keep calm and I wish years ago I'd have some people are born leaders some people lead erm like they lead because they're born leaders because they can do it they're calm collected they've got that in them some people people who are on like salespeople who are interviewing the ordinary people you've got to be calm you've got to be able to handle yourself and not to lose your temper its going through that process isn't it

Yeah it is was there a particular occasion where you felt like you said its gradual but was there an occasion where you thought hold on a minute need to start doing this or I've learnt to do this was there a particular point where you might have realised

Well one time was when this is about three years ago and I thought well it's when I went to the hospital for a physio and I left (wife) in the erm the waiting room and when I came out she wasn't there she'd disappeared and of course they had to get the police and erm and then I didn't understand none of the neighbours knew the situation cause there was no warning signs that was the one which that made me aware you can't leave her on her own and erm its about four years ago and the thing was the police turned round and said you go home go home now they were very abrupt in one way erm and we're gonna come and search your house I said she's gone missing here and I lost my rag a little bit there and I only realised afterwards it was what they normally do through procedure and really they couldn't have done enough at the end of the day in fact I did write a letter to the chief constable who was in Liverpool Merseyside Gordon Howe at the time thanking him for the police what they did and they found her 8 o'clock at night believe it or not in Sherdley Park from 10 o'clock in the morning they sent the

helicopters out but you raise your voice and you shouldn't do that and I thought I've got to learn from that and on a slow process I've done it

Learn from mistakes

Yeah gradually right so what personal characteristics would you say have helped you other than you mentioned you stay positive anything else about yourself

What's helped me a lot is these centres carers centres other people have helped me hearing their stories hearing their stories and how they've coped and what to do and going to these carers centres and erm asking people for help can you help me to do this and can you help me to do that and right along the line people are there to help you if only you will ask for help they will help you but to be at home and not ask and think about things all the time you won't get no help I don't know what will happen

Help from fellow carers

You've got to go out

You've got to go out it's there to be had you know there's people like yourself you know you've come in and had a little talk we've talked here now

No there's no limit on it what advice would you give to someone in the same position as yourself

What advice the advice I'd give I'd try and give them like I've just said before about the help and I'd try and take them through different things not everything because they've got to come into situations themselves and being able to handle it themselves in each situation nobody wants anybody to tell them the worst things that could happen in 12 months' time like nobody tells me what can happen in 12 or 18 months' time I don't know people may know what's gonna happen I don't know because they don't say all they say is everybody's different which they are all I can say is you know your person you're looking after you know

Own experience

exactly the ins and outs you've been living with them you know what they like you know what they don't like and they suddenly don't like a certain thing if they've never liked it through their lives don't put that onto them try to treat them as best you can as you always have you know that's the way try and keep yourself calm that's the only thing that's all I can think

Know the care recipient

Brilliant is there anything else you'd like to talk about that we've not covered anything you think I've forgot to ask any other aspect of being a carer that you'd like to mention

I think actually being a carer is you never think its gonna happen to you really you always think it's gonna be rosy but really lots of things can happen to anybody different people have to put up with different things all through their lives and they have bereavements and if they lose their children and I hear all kinds of stories and you listen to the radio television and everyone has problems and things and really the problem if you call it a problem it's just something you've got to live with I mean it can happen any time you've just got to carry on with it and do the best you can and I think really if you can say well I've done the best I can and I always tell my daughter this when I see her about her children bringing them up and I said whatever happens if you can say to yourself I've done the best I can for them what else can you do you can't do anything else and that's what I say to myself if ive done the very best I can that's all I can do and that's what I'd say to other people as well just do your best

Inevitability

Done my best

Do all you can

Because everyone's different they may not be like I am I mean God forbid I wouldn't say you just do what you think is the best you can possibly do every

morning people probably do it better than what I do I don't know I really don't know it's just

Everyone's different

Everybody's different just try and do your best you know what your wife likes or what your husband likes or how you can cope and if they shout that's another thing you've got to go along and why do they shout you've got to try and work that one out it's another thing which I don't have really which they have see

Work it out

Right

But its working out isn't it

Working it out as you go so how would you describe yourself now then

I'd describe myself now as I've just brought (wife) in here for a couple of hours you know and erm I've told them I'm taking her home on the bus and everything and I just describe myself as happy I'm happy I'm happy I'm happy and I think really I say to her are you happy and she says I'm happy and what really erm affected me really the other night Warren was erm I'd done everything and things had happened you get your good days I suppose and I was tired and the best thing on a night is when we're just sitting down around about 7 o'clock and everything's washed up and I'm sitting down and (wife's) sitting down alongside me and erm I'm bit tired and television just going over my head and I just happened to say this was the other week I said to my wife (wife) ey (wife) do you love me because I needed some sort of response you know and she turned around and she looked at me and she says I don't know where it come from and she said (mr Go.) I really love you do you know what Warren I broke down

Happy

Stimulation

I bet you did

When she said that that's the only time she's ever said it she doesn't talk

She must appreciate everything that you do

And my God everything I felt great

It reaffirms what you've been doing

I felt great and I know she does and that's the way I'm talking to you now that's the way I'm finishing erm everything's alright Felt great

Brilliant

Whether you'll come back and see me in another couple of years' time

Well we don't know do we nobody knows

But you're always welcome to come to where I live in Rainford (gives address) bungalow and have a cup of coffee or whatever but take us as we are

I will do I certainly will

Appendix 13

Time 1 list of codes

T1 - acquisition of knowledge
T1 - adjust
T1 - annoyed
T1 - behaviour problems
T1 - change in priorities
T1 - change in relationship with CR
T1 - constant vigilance
T1 - coping
T1 - don't want respite
T1 - free time
T1 - friend advice
T1 - friends from dementia
T1 - giving back
T1 - good relationship with CR
T1 - groups
T1 - guilt
T1 - health service problem
T1 - humour
T1 - independence
T1 - keeping busy
T1 - keeping stimulated
T1 - life back
T1 - loss of car
T1 - lost social life
T1 - maintaining continuity
T1 - negative future
T1 - negative spell
T1 - new responsibilities
T1 - no future expectations
T1 - no need for support
T1 - nothing now
T1 - one step ahead
T1 - personal qualities
T1 - positive outlook
T1 - proactive
T1 - protecting children
T1 - recognising limitations
T1 - resignation
T1 - respite
T1 - respite decision
T1 - routine
T1 - shared experience
T1 - social services
T1 - spiritual

T1 - stages
T1 - staying positive
T1 - stern
T1 - support group supportive
T1 - therapies
T1 - turning point
acceptance
adaptability
advise
compartmentalize
confidence
coping strategy
daughter support
downward comparison
expertise
family relations
family support
finances
friend
friends from dementia
health
health and social care
health maintenance
hobbies
humility
humour
information resource
keeping busy
maintaining normal activities
mother - supportive
networking
old friends
openness
organisation
other services
patience
positivity
previous experience
pro active
realistic
relationship quality
request help
self awareness
self preservation
social cohesion
social participation
social support

Appendix 14

Coded time 2 transcript (Mr Go.)

When I was calling you up, did you say, was it, your brother wasn't so well? Or is he ill?

He's had his hip replaced but he's due for another hip.

How is he in himself?

He's eight years older than me, never ever got married. Lives on his own. So, again, he understands my situation I'm in, but on the same token they don't realise the *whole* situation if you know what I mean, because when (wife) comes here to the Kershaw, he tends to say 'what are you doing today?', erm, 'can you get me this shopping', 'can you get me that shopping'. I mean he's my brother and I mean, it ties you down, really.

Doesn't understand

Ties you down

Yeah.

And, you're tied between, erm, doing one thing and then doing another. Everything takes time. Although they say that (wife) could leave the house at half past nine and when the bus comes be ready for half nine, sometimes it's half ten.

Time

Yeah.

Quarter to eleven. And before you know where you are –

The days gone.

Your morning's gone, the days gone. That's the situation, that's why I said to you when you rang up.

Yeah, you can never tell.

Well, we've got the nice weather coming now as well and I like to do the garden. People say 'well you should get a gardener in'. I *don't want* a gardener.

Independence

Yeah, you want to do it yourself. How do you spend a day off now? In an ideal world what would you do? Just relax?

My relaxation is well, for instance, the last two days, erm, what happened I've had a shower room fitted. Home adaptation

Oh yeah.

That was one- I needed that, to get that. And erm, also, I've been running round to the mobility shop where they have different equipment, which I've purchased kind of thing.

And erm, that was say Monday, Tuesday. Course, that was the bank holiday this past week.

Yesterday for instance, Wednesday, I started the garden. First time, really, as late as this year, erm – first time I've been in it. Gardening

Yeah.

And it's full of weeds.

Well it will be, yeah.

And, I just enjoy doing it. And I have my lunch, I have my proper dinner at lunch time, and I've pretty well finished that by three o'clock, and every so often I make a cuppa tea and that and I'm sitting down on the bench sitting outside having a cuppa tea, great. Leisure But I have to watch it because, with my spine. I've got spinal stereosis which is – I've had an operation on me spine which wasn't successful. And, erm, it just, it's not life threatening in any way - but it just gives you aching and everything. Health problem

Have you always had that or is it a recent thing?

Well, when I think back ten-twelve years, I started going to the doctor with backache – course- he said sciatica with backs and things and everything.

Yeah

And he kept on 'sciatica, sciatica' and it ended up, eventually, he said 'I'll just send you for a scan'

Hm.

And they found out with the sterosis and the next thing, I went into the Walton Centre in Fazakerley and had the operation. And they slotted me in, kind of thing, because of (wife) Surgery

Your circumstances, yeah.

But the consultant who I was seeing, who's a great consultant, didn't perform the operation, he got somebody else to do it.

Right.

Because they got me in on a cancellation. And, erm, although I've been back to him since and he said I need another operation, I said I don't want any more, so, that was three years ago.

Yeah

(Wife) had to go into a care home for three weeks. Care home

When was this sorry? When did you have that done?

It was three years, so what year would that be?

2012-ish?

Yes it was 2012, and, erm, she was in a terrible state when she come out. Terrible state

Yeah

All her legs were all scratched. It took me six months to get her back to as she was. Recovery

In those three weeks?

Yeah, three weeks. And, erm, you see with (wife) – she doesn't talk. And it's hard, when there's most people with Alzheimer's or Dementia, they do talk

Yeah

And it's hard in one way, and another way, it's easier because you don't get the situation some people have when they start repeating themselves and also they want to go home and they want to do this and they're always, and they could be, lose their temper and, erm, start saying things to you or swearing at you or whatever I've heard people say. (Wife) doesn't say anything like that, so I do - that's one thing I don't get which is – what she thinks- I try and get into her head but I don't know, she just smiles and laughs and pulls faces. Downward comparison

Laughs

Yeah. How long has she been that way where she's not really saying much?

'Bout five, six years. Five years, yeah. And it's all been mini strokes actually. It starts with mini strokes. But since I've last spoken to you which was probably a couple of years ago, really. Erm, since then, her mobility has dropped down a little bit more. She stoops now when she never stooped before with her head and her mobility is, erm, is, not erm she can't walk that far. Although, she can walk 'round in the house. No problem with anything like that. Erm, I noticed in the last six months as well, lifting her foot up, she can't lift her foot up. She comes to a step and the brain is telling her to lift her foot up and it won't connect and she can

lift her foot up. And I was first aware of that, probably say twelve months ago. And it started off, when we used to go upstairs in a store like Marks and Spencer's, on the Deterioration escalator. And we were half way up one time and she started falling. She fell down the escalator. So that was the escalator that was the lifts. But erm, that's her mobility, and just recently I got her a wheelchair because she can't get up the steps on the bus which brings her here to the (day care centre). And erm, but otherwise she's pretty well- oh there's something else. Feeding as well. That's something else. Her continence has been like that for a few years.

Right.

Which I've got over. Each stage you come across brings something new to you, which affects you first, you don't know where you're gonna end up and how you're gonna Solve problem manage but you can sort it all out, you work the best way 'round it, you solve the problem and then, it's not a problem anymore. But then something else arises, where, erm, you've got to start all over again. And whatever arises, takes more time and the latest thing is eating.

Yeah.

I used to -of a night time when she was at home with me and not had her lunch here - I used to cook her dinner, just give her not over faced and she'd tuck into it no problem. But now, after having me own dinner, sit down, I've got to feed her now you see.

Assumed more responsibilities

Yeah.

And erm, at first when you see them, it's like you can't believe it because you think – you actually think – they're having you on. Because you put the plate there and you know she can probably pick it up with her fingers, she probably can, but if its anything that's a bit sloppyish or whatever- chips are probably alright – the next thing it's, it's like a child all over her face.

Is it?

So it's easier to feed her, and she quite expects you to do that you see, and that all takes time again.

Takes time

Of course it does, yeah.

So, whereas teatime, we're probably at the top about an hour and it takes about two hours to do.

You've got to have yours and then you've got to-

Well I have mine as I'm giving it to her, you see. So, but erm, again, I'm getting over that.

Admits limitations

And of course here, they look after her and like, they give her one-to-one kind of thing for her lunch, she comes into a separate room. What I'd do without, oh, I don't know what I'd do without this centre. But because you need somebody, I can manage my wife (wife), there's no problem with that, but could I manage it seven days 24 hours seven days all the time? I don't think I could.

Support workers valued

No.

Them three days I get off now- I started off with one, then two now its three, actually she's been coming here now for about 6/7 years and she's been diagnosed 12 years, see? So it's a good help for me because I could do things, whereas before I could leave her in the house

Increased respite

doing jobs herself in the early stage, it wasn't so bad, and as long as she could see me outside and everything we'd be alright. We can't afford to do that now.

No.

But, erm, its not all bad news though, really, do you know what I mean? It's because, erm, she goes to the (day care centre) Monday, Tuesday and Wednesday. We go to the Alzheimer's on a Thursday in the town in St Helens and Friday we usually go shopping. Now, she's still able to push the trolley around the shop and we've been doing this now for a few years.

Not all bad

Routine

Yeah.

And when it first started, she started with, erm, with people's going past, and there was more stuff in my trolley than any, when we got to the tills, I never really realised, I thought 'I never put that in'. but erm, at one time, early days, turned my back like a child again she'd gone with the trolley.

Right.

Now her mobility is a bit impaired she's not able to do that, but she was off like a shot. I was running up and down the aisles, my heart was pumping

Panic

I bet it was.

And if there was anything wrong with my heart it had gone there.

And the assistant said I'll put her name on the tannoy and I said it's no good on the tannoy. So, at the end of the day, I didn't know what to do and I thought I'll just nip outside… and she was standing by the car. I couldn't believe it. With the trolley full of food that we hadn't paid for. So, then we had to push the trolley back, and low and behold, wherever we go now they know us.

Really?

People with dementia you see, they tend to, the carers – I don't know. People are hard, probably harder than me. And it is easier to go around the shops yourself and even have

someone in the house looking after your wife or your husband while you go yourself but I couldn't do that. Not at this moment in time – I never say never, there may be a time where I have to do it. Everybody knows us and they help you. I'm not kidding you, they really help you around the store.

Never say never

Is that because you've asked for the help or do they just-

No, they've just, over the years which we've been going, at first, with (wife) not talking, speech is the give away with Dementia. When you meet somebody normally your partner, your wife, your husband starts joining the conversation, and it's a dead giveaway to the other person because of the repeating. That never happened to me because (wife) never spoke.

Speech

Yeah.

So she looked great, it was me doing all the talking. But over the years and meeting people especially in the shops and things, they noticed how she is and how she's deteriorated slowly each week. I don't mean the same shop, it could be Marks and Spencer's, Gemini, you'd go there and we used to go upstairs to the café 'oh sit down, we'll wait on you', I'd give them so much money and they'd get whatever we wanted.

Deteriorated

Shop assistance

That's great.

They'd wait on us. Even when, what used to happen, I used to take (wife) for clothes, I used to take her to Marks, and I'd say 'can you help me?' in early days because I didn't really know the sizes and whatever, and low and behold, the assistants there in Marks and Spencer's would fall over backwards and help you. All bras, everything they'd help you with. Even like now, some days when (wife's) here at the Kershaw, I do go to Marks on my own because Marks gets really crowded, it's very hard as well with it being such a vast shop especially in Warrington

Shop assistance

It is, its massive.

And, I go on my own and I buy clothes even if I'm uncertain, they know me. Different assistants say 'how is your wife?' 'cos they know me. And, erm, they help me 'do you want anything?'

And that's because you've taken her

I've always taken her, all the time. They do, honestly. And, erm, they're good. The people are very, very good.

Who's been the most supportive to you, would you say?

In what way?

Well, generally. Say recently have you – you say you like to do it yourself – but if you've needed support and help, who's been the most supportive?

Carer support

I wouldn't say anyone in particular, I'd say everyone. Everyone. Everyone who knows you would support you. I couldn't pick one person, I mean, it depends on, you could name all– I go to the Alzheimer's group. They're all there. They have carers there every week. There's the care centre in St Helens, they'd fall over backwards to help you. You can go in and have a cup of tea on your own or with your wife, any time at all. I go for therapy there for my back every few months. I get a massage there.

Everyone supportive

That's not bad is it!

That's there! They're supportive. Very, very good. I cant say one. (Day care centre), look at the (day care centre) here! It's spot on.

Yeah.

And even people with the council, in St Helens council. People I know. People I've spoken to. They'll help you.

Council support

Yeah.

They've helped me. Honestly. I know you must hear all kinds of stories and people have it difficult and things like that. But there is support out there.

Support is available

You've got to ask for it. You've got to go looking for it.

You've got to ask but asking one person leads to another. If someone asks me, I tell them to go to the carers centre in St Helens. And for a start, just to start off, they would help you right along the line. In anything at all. That's the initial start for anybody. And I think that's where I started. Signposting

What is it about the carers group do you think?

The carers group?

What's good about that?

Well, we've been coming here for quite a few years, we've known that many people and there's a lot of, erm, I know the people and sadly some of the partners have died over the years, and erm, its just – you can't believe that they've died some of them because some of them have even, I think, looked better and been better than what my wife is! But anything – it can happen any time. But here its good, its only two hours really, but erm, here its talking to people. And in early days, they used to talk about, in any group – any supporting or carers group – you can talk to a man or a woman who you've never probably seen before, and before you're finished after a couple of hours, you've been talking all of the nitty gritty which you wouldn't even talk to your relatives, your son or your daughter. They know all what goes on – your family – but they don't know everything what goes on. They don't know because they're not there 24 hours a day. But these people at the carers group, here, they're doing it the same as yourself and some of them are a damn sight worse than yourself, they're having it very, very hard. I mean some of their husbands or maybe their wives, I don't know, stories they could get aggressive, they have all kinds of reactions, I know one thing, my wife's very, I don't get any of that, and that's a blessing. And I always feel, after I've been here talking to different people, I feel like a new person. I feel great. And I don't feel – my life's not so bad. They're going through it more than what I am. People say, you're

Disbelief

Talking

Downward comparison

good, you're doing well. I'm not – they're doing better than what I am. I'm just doing what I can.

Yeah

But, you know, that's all about it. I don't know If you want to ask me anything else.

Just a couple more. How do you spend – so with your wife now, how do you spend a typical day now? So you've got your days off, you mentioned breakfast when you get up, you take two hours doing that, what else would you do together now?

Well, breakfast isn't so bad, it's the evening meal really. Its only flakes for breakfast. What we tend to do, especially when there, well we've had the winter months which again you worry about colds and getting outside the house and things like that, but you get a build up what you've got to kind of do. Put the washing, you don't do all the washing and everything, you try and do that on your days off and things, but the tendency is every, if I'm on a Saturday for instance, I get up – I'm always up about six myself- and I have my breakfast, and I get (wife) up around about quarter past seven and I've already had my breakfast and I'm dressed and things like that. And what we normally do, believe it or not, after she's had her breakfast and she's not very long taking her breakfast, we get a shower. I have all of her clothes ready and more often than not - im not saying its repetition every week where we go where we go to the shops every week because some weeks ive already got stuff in kind of thing –

Routine

Yeah.

This sort of day like today – a nice sunny day- we'd be out in the car. I could erm, like last weekend, we could go to Crosby or Southport and I know she – I recently got this wheelchair so – really she can't walk a distance so it's ideal a wheelchair. But, in saying that, even if we just get out the car and sit on these benches and there's children playing and there's people walking around, she's amazed with the people watching, and she's very happy doing it. She's made up watching

Out and about

And it's something you couldn't have done at home.

Again, if you're at home its either me sitting at home, we've got a nice garden in the back and I know she's only sitting outside and she's looking at the garden and maybe I cut the grass and it looks nice, she doesn't see it like I see it. And its, unless there's someone there and there's some other entertainment, it's probably a bit boring for her really.

You need that stimulation, it's like anybody really isn't it?

You need to get out. New Brighton is another thing, we go to New Brighton and we nip into Morrison's and have a coffee in Morrison's and the promenade, New Brighton is absolutely marvellous, there's that many people there in New Brighton. Out and about

You can imagine what it could be like now can't you?

Honestly, Warren, she's happy. She's a happy person. I say to (wife), I try to get into her head and say 'are you happy? Are you happy?' and I know for a fact that she's happy. Happy

Yeah.

In her own way, I'd love to know what's ticking in her brain, I know she's not sad, she's happy, and I'm happy as well. I am happy, with her. Happy with her

Yeah.

And as I've said to the carers in the group and all that and they say 'oh you're doing this and' but, I've got my wife home with me. You haven't got your husband. They've lost their husband, one of them or two of them, and to lose their husband and to be on your own, that's the worst thing that can happen to anybody I think. Downward comparison

Yeah.

I mean, we've been married, I met (wife) when she was 17 believe it or not, and erm, I didn't know whether I was gonna get married or not but she wanted to get married. Honestly, I really didn't. And, and, I wasn't sure. I was 22 when I got married, I was two years older and she was 20, and, erm, I was having to say just before the wedding about, I

said, do you think that this – it's all been of a rush this? Getting married? I mean, how do you know it will work?

Yeah.

And she was positive, she just said 'don't worry about it. We can always get divorced'. That's what she said to me. And it threw me, it really threw me. It did because; I wasn't that type of person, honestly. She was a positive one. She's the person – I'm not kidding you Warren – my wife is the person she's made me become. I've become the way she did, I was never like her. I was the one who wouldn't take chances, who wouldn't do this. She was the one 'we'll do this' I was the one 'oh can we.. oh we don't…', I was the jitterer. But,

Humour/ positive one

Wife changed me

Is this since this or has that been gradually over the marriage?

Gradually over the marriage. What happens in the marriage, and it doesn't matter really. I mean some marriages; you love each other and it's all a game with luck. And I'm not saying that someone who splits up it's a bad…it may have, we may have split up. I don't know. It happens doesn't it. And it's all down to love, a lot of it. I suppose if you're carring on with somebody else. That's a different story. But if it doesn't work, it doesn't work. It's all down to luck. And over the period of time you become, two people become, each-other. Although little bits of your wife and little bits of you to her annoy you to each other, all the things that you annoy get sorted out over a period of years because the other persons pulled you up about them. and because you love them, you try and change. And you become as one.

Two become one

Yeah.

You become as one and you don't realise it, she gets a bit like you and you get a bit like her.

How has your relationship changed then? Has it remained pretty similar or?

I love my wife the same, even more now, than I've ever done. And God forbid and if we'd have been, if she'd have been alright, we were alright

Good relationship

together. We were great together, and I mean, there's loads and thousands of people the same as me. And there's a lot of people happy. Again, it's how it goes isn't it, and its luck. But, erm, I'm not kidding you, we were opposites, and (wife) was – I was so Stubborn. And she was a bossy so-and-so. Honestly, people would say at the start that it wouldn't work, because – I don't know. I was so funny, kind of thing. And, erm, I mean her family wasn't – it's a different thing you see – my family never loved if you know what I mean. Never showed a sign of love. Although they loved – (wife's), my wife's family, were the loving type.

Opposites

Affectionate?

Affectionate. Huggers. And we weren't huggers. I'd go, my sister would never kiss me or anything like that, and, er, what used to happen, (wife) in early days, she'd go to her family and would be arguing with her father and I'd think 'what kind of relationship am I getting in to?', but just before we'd be leaving they'd be hugging each other. And everything would be forgotten. So stimulate, and that's exactly how my son was with his mother.

Affectionate

Oh right.

My son was like that. And over the years, I've just become a hugger. When I used to see my sister I'd put my arms out and she'd turn her face away. She'd turn her face away.

More affectionate

Yeah.

Now, I don't know what it is now, I love I mean putting my arms around people. It just shows affection. I know you don't do it to everybody you've got to, you can't be like that can you? But we are, honestly, and it's her who made me like this.

Wife changed me

Yeah, and you've probably made her.

I'm a better person, honestly. A better person through her. And, erm, through all these years, she's looked after me. And she showed me, so… I've gone on and on and on haven't I?

No, no. I've just got one last question. Erm, you say people become, I don't know, can you become … how do I word it… if you can become successful at being a carer and doing your best, what do you think it takes to be?

The thing is, Warren, If you'd have asked me that 20, 30 years ago, I'd never be a ca- I'd never be able to do a carer's job.

Yeah.

I'd never be able to do that. I'd- people don't know that, in a lot of ways, for instance someone who does something in the war or a hero, they don't know the situations that you're gonna react yourself. Your own body. Whether you're going to be a coward, or whether you're going to be a hero. And that's in one sort of situation. But, like a carer for instance, when something happens like that, some men or some women can't handle it.

Yeah.

and God forbid, I don't know – it's the way they are. I don't know. You don't know what's in you. That's all I can say. It's hard to explain.

Yeah.

But with myself, I actually do pray to God – I'm not a religious person – but I thank God that he's made me the way I am. I really am a carer. And I really love looking after her. And I know for a fact that I could look after anybody. If you've got that bond and you want to do it and you can see the situation they're in, and especially with someone so close to you, your wife or your relative, I'd look after them. I really would. And it's something you can't explain, because it only happens when you've got to do it yourself. But people amaze themselves, what they do. I'm probably not the only one, I mean they must think 'I didn't think I'd do that so many years ago' and that's how it all is, really.

Love caregiving

Does it get any easier over time? I dementia, there's a deterioration isn't there.

Well you don't realise – does it get any easier? It, I mean, getting easier in so much of what you do.

Your routine, you know what you're doing.

It doesn't make any difference. I think it couldn't be any harder than what it is. What gets the hardest and what will affect you the hardest in the future is being emotional. That's what gets to you. Being emotional. Not the work you've got to do, the work I've got to do doesn't affect me and I'll go on and on and on and I know for a fact that it won't affect me, I'll keep on doing it. And that won't get any harder. I know. Whatever (wife) comes up with next

Emotional

Caregiving no harder

You'll deal with it

I'll deal with it. But what will get harder for me is emotion. Being, I can't help, I'm an emotional person. And, erm, to see someone you *love*, you know, that's how it affects you. But it only comes to you when you're pretty well on your own and things like that.

Emotional

When you stop, isn't it. If you're on the go all the time I guess you wouldn't.

No, and it doesn't happen all the time, just sometimes you do go down, Warren.

Of course.

You don't know what it is and you go down and you're very emotional and you just offload and the next thing is you spring back up again, because again, there are always people worse off than yourself. There really is. I always think that. I mean children. Children who are, you've got to look after children, I mean I'm looking after my wife, we've had a really good life, we've had good times, we've had everything. But to look after a young child is very, very hard I would say. That's another thing you asked me about, caring for is, to look after a child I don't know how you'd go with that. But it would be very, very hard.

Spring back up/downward comparison

Downward comparison

Last question: what's one thing you have learnt since our last interview? Have you learnt anything that you'd share to another carer who was perhaps just coming into it?

I'd say to another carer that I've learnt that it's not all bad. It's not all

bad. I mean, although you go through stages and each stage is different and each stage is hard, but I'm working each stage, you quite surprise yourself when you eventually get through that stage. All these stages like incontinence and other things when people are shouting at you, you learn to react. And the way I've learnt myself is how to handle things. Talk and never argue with them, just talk very very quiety, treat it as a joke and always – if they want to keep something let them have it, and then after five or ten minutes, don't try and take it off them. And the thing is, is just, erm, be calm. Because don't lose it, don't shout, try not to shout because at first you do shout and I've shouted myself because you think your wife, your partner, is having you on. And you shout 'come on, come on you can do this', 'you can do that', and you may shout loud. You live in a detached house, no one can hear you, so what? But thing is, when they look at you and they have such a sad face, that's when you get emotional and you think 'what am I doing here, no way will I do that '

Stages/learn to react

Advice

No, and that's when you spring back isn't it.

I always turn around now and I always praise my wife. What I always do now, I always praise her and say 'you're the best', 'you're great, you are', 'you're marvellous', 'aren't you great'. And when, because I'm saying that to her, her eyes – I don't say you're horrible or anything like, I know she can't talk, but she can listen, she can hear me. And I say 'you're great' and 'Oh you're great you aren't you?' and she lights up. And her hardest part is getting up off her chair, you've got to kind of pull her up and I go into 'one, two, three, come on', 'one, two, three, you're great you are!' and she does get up and its marvellous to see her light up. It's like talking to a child. And if you're a child it's the same. When we were younger and we were bringing up our own children, I didn't realise.

Praise

Light up

You'd shout at them. You'd do all kinds of things. As a parent, you'd get annoyed if they'd done anything. I mean, this looking after my wife, if I was starting all over again now with my family and bringing my child up,

I'd definitely bring it up a different way than what I brought mine up. I really would, not that they've turned out bad in any way but there's a way of handling them. And I don't mean, I mean as a person, they're just like you and I, and you love them. You love your child, you love your wife. And if you praise somebody and say you're great and you love them, you've got to tell them you love them. And if you say that, you'll get a good reaction.

Praise

You see it and then that fulfils you.

And I get my reaction off my wife (wife). That's how I handle her. I mean I know they don't do this, they don't do it here, they have it harder than I have it hard, I'm sure they do, but they don't talk to her like I talk to her. That's how I handle it. And it's not *all* bad. If someone is starting off like that, if they can learn to be calm and it comes on a process if they can only do that, there's good things. You can have a *laugh.* My wife laughs my head off! Especially when I said to her 'come on, you can clean the house today, I'm fed up doing that' and I was laughing when I was saying it and she looks at me as if to say, she does honestly!

Downward comparison

Not all bad/humour

It's contagious isn't it, positivity.

Yeah honestly, there is. There is a way to.

So that's your message then? That it's not all bad.

It's not bad! It's not bad, Warren. Honestly, it really isn't bad. You've seen my reaction haven't you and the way I treat her and I love her to bits and you tell her you love her. When I put her to bed of a night, I mean, I have to put her to bed, I put the clothes back, I walk her to the bed I have to sit her on the bed – she can't get on the bed, she can't get into the bed- so I sit her on and I swing her legs around and then I took her in. Put the clothes in, two single beds, I'm in the next one because we've got quite a big room and I took her pillow round up like that and she's looking at me and I say 'I love you, I really love you', and erm

Love

She knows.

She knows. She knows. And erm, I give her a kiss and everything like that. And that's it. And I'm quite happy, because I know she's happy.

Yeah, yeah and you can see it. she listens.

And I've gone on and on and on!

No, you've not!

What's on that tape!

(Laughs), that's the question isn't it! Thanks a lot, I'll stop it.

Appendix 15

Time 2 list of codes

T2 - acceptance
T2 - adjust
T2 - apprehensive future
T2 - behaviour problems
T2 - book comfort
T2 - bottle up
T2 - challenging health professionals
T2 - change in relationship
T2 - charitable
T2 - child comparison
T2 - children supportive
T2 - content
T2 - coping
T2 - cousin supportive
T2 - CR behaviour
T2 - CR company
T2 - CR insight
T2 - day care
T2 - denial
T2 - disposable income
T2 - DNR
T2 - don't see friends
T2 - don't want home help
T2 - downward comparison
T2 - empathy
T2 - family support
T2 - family visit
T2 - free time
T2 - friend competing demands
T2 - friend dropped out
T2 - friend visit
T2 - friends from dementia
T2 - funding
T2 - giving back
T2 - good health
T2 - good relationship with CR
T2 - grandchildren supportive
T2 - gratification
T2 - groups
T2 - guilt
T2 - health service help
T2 - health service problems
T2 - helping others
T2 - holiday alone
T2 - humour

T2 - independence
T2 - in-laws don't understand
T2 - innovative
T2 - inst brought family closer
T2 - inst decision
T2 - keeping busy
T2 - keeping stimulated
T2 - learning curve
T2 - life back
T2 - lost companionship
T2 - lost extended family support
T2 - maintaining continuity
T2 - memory fades
T2 - negative emotion
T2 - no conversation
T2 - no distress
T2 - no guilt
T2 - nothing now
T2 - own company
T2 - personal qualities
T2 - prepared
T2 - recognising limitations
T2 - relief
T2 - reluctant for help
T2 - respite
T2 - respite decision
T2 - respite negotiation
T2 - routine
T2 - shared experience
T2 - sister support
T2 - social services
T2 - staying positive
T2 - stepchildren don't support
T2 - stepchildren no relationship
T2 - stoic
T2 - support group friend socialising
T2 - tension
T2 - therapeutic
T2 - turned down medication
T2 - turning point
T2 - unhelpful support
T2 - volunteering
T2 - wish near family
T2 - women's work

Appendix 16

Chapter 6 list of codes

children - adoptive
children - conflict
children - didn't speak to
children - don't see often
children - intimacy at a distance
children - supportive
children - taking control
children- divorce
children support carer not recipient
daughter - carer reassures
daughter - don't see very often
daughter - good relationship
daughter - intimacy at a distance
daughter - supportive
daughter - wish for
existing friends - couldn't speak to
existing friends - don't see often
existing friends - drop out
existing friends - guilt
existing friends - intimacy at a distance
existing friends - last resort
existing friends - let me chill
existing friends - shared experience
existing friends - socialising
existing friends- supportive
grandchildren - changed identity
grandchildren - don't see often
grandchildren - intimacy at a distance
grandchildren - supportive
great-grandchildren - don't see often
in-laws - absent
in-laws - intimacy at a distance
in-laws - supportive
neighbours - carer is open
neighbours - giving back
neighbours - supportive
niece - intimacy at a distance
niece - supportive
church friends
other group - shared experience
other group - supportive
brother - supportive
siblings - don't see often
siblings - see regularly
siblings - sister not supportive

sister - didn't speak to
sister - don't see very often
sister- supportive
son - intimacy at a distance
son - relationship poor
son - see regularly
son - supportive
son- don't see very often
support group - downward comparison
support group - socialising
support group - supportive
support group friends - couldn't speak to
support group friends - shared experience
support group friends - there for one another
support worker - couldn't speak to
support worker - supportive